Roles and responsibilities in understanding, accepting and adapting to an uncertain chronic illness trajectory

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ABSTRACT

The aim of this qualitative study was to explore the lived experience of chronic illness during and beyond diagnosis within the context of relationships between patients, family carers and service providers. Findings focus on the ways in which people with chronic illness and their family carers became aware of the prognostic limits of medical information, and the psycho-social processes involved in managing the uncertainty inherent in the illness trajectory within a context of creating and maintaining relationships with favourite members of staff. This has implications for the current policy imperative for self-care and challenges the assumption that biographical support and self-care are mutually exclusive concepts. Findings suggest that it is necessary to combine the promotion of independence with recognition of the importance of continuity of carer across the illness trajectory. This has implications for the introduction of case managers for people with complex chronic illness.

Humanism was adopted as an organisational framework that called for primacy to be given to the voices of patients, children and family carers. Symbolic interactionism informed the interpretive premise that this study is only one representation of multiple realities, and grounded theory was used to guide the iterative process of data collection and analysis. Data were collected in two phases; phase one in a general hospital setting with stroke patients, phase two in a special school for physically disabled children with a variety of chronic illnesses. In phase one, observation and interviews were held with stroke patients (n = 9) and their family carers (n = 10) during the hospital stay and following discharge from hospital. Emerging themes influenced the design of a qualitative questionnaire used with service providers (n = 31) to explore contributions to care and interpretations of progress. In phase two the study was extended to explore perceptions held by physically disabled children (n =

12) in a special school setting and their informal carers (n = 16) about the lived experience of chronic illness. Observation and interviews were used with children, based on photographs they had taken. Data from service providers (n = 42) working within special education were collected using questionnaires.

Data taken from different diagnostic and age groups were compared to explore commonalities and differences in representations of chronic illness. Common themes emerged that cut across diagnostic groups and service responses to those groups. The themes are presented in this thesis as three interdependent psycho-social processes intended to manage the uncertainty inherent within the illness trajectory. The processes of understanding, accepting and adapting to uncertainty emerged as central categories. Chronic uncertainty was managed via processes of information management, making comparisons with others, making biographical comparisons with one's self, and maintaining continuity of carer. Findings contribute to increased understanding of the processes of care available to people coping with chronic illness within a multiprofessional context. The innovative nature of this study informs knowledge on several aspects of research into the chronic illness experience, namely, methods of data collection with vulnerable people, practitioner-research, managing multiple pathology, the 'expert patient', chronicity, and specialist care outcomes.

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Thank you to my parents, for their gentle encouragement. Most of all I wish to thank my husband, Andrew, who taught me to meet chronic illness with dignity and joy, and my sisters and best-friends, Catherine, Rebecca and Linda who showed me that carers need care too.

Author's declaration

No portion of this work has been submitted for any other award of this or any other University.

Chapter 1

INTRODUCTION: Setting the scene

Background to the study

Providing a service for someone with multiple, long-term needs creates a demanding set of issues facing health, education and social care organisations, most of which are geared towards specialised, acute management of those needs. The multiprofessional teams which arise to meet these needs have been the subject of intense interest, focusing attention on individual and collective goals of care, definitions of health, and the interface between informal and formal care. This, coupled with a client voice growing in strength and political influence, has led to frustrations, contradictions and opportunities in the daily lives of professionals and clients alike. For my part, working clinically with terminally and chronically ill people, it is these issues and tensions which have shaped the direction of the project in many ways. This introduction summarises and synthesises these issues in terms of aims, principles, and methods.

This study began life as a result of shared interest in issues concerned with multiprofessional practice in schools and hospitals. Early on in the study, I became concerned that interest in multiprofessional working appeared to neglect the voices of the most important people in the picture; the patient and family. As a practitioner, I became increasingly frustrated with organisational constraints that forced me to react to patients according to their diagnoses and not their long-term needs and wishes. For example, the 'leg ulcer in Bed 3' was given care according to her bio-physical requirements rather than her needs and wishes as a human being with 10 years experience of living with pain and discomfort. While there is nothing new in identification of this tension, my work as a staff nurse in a local hospice stimulated

an interest in the ways in which the ethos of hospice care offered an alternative to the acute, curative approach seen in hospital wards. The primacy given to the wishes and needs of clients and their family members in the hospice setting formed a set of questions that were to stay with me concerning the conflict between needs and resources, power and voice within organisations, and the role of clinicians in shaping the illness experience. The stimulus to go further and address meanings and experiences of care was brought about by numerous clinical encounters, an anonymised amalgamation of which is outlined here.

> *Jill is a lady who suffers from a progressive chronic illness that affects her muscles and coordination. She lives alone in sheltered accommodation and enjoys the daily contact she has with her son, home support staff and district nurses. Her elderly neighbour visits every evening to have a sherry and fill in the crossword puzzle with her. Recently, Jill's physical condition has deteriorated and she has suffered a number of falls. These have been brought to the attention of the GP who feels strongly that Jill should give up her flat and move to a nursing home where she would receive 24-hour care. Jill worries that she would not benefit by moving away from a support structure in which her needs are recognised and understood by people who have known her for years. Reluctant to leave her home and friends, Jill sees her physical deterioration as simply another challenge in a series of challenges that she has been helped to face over the years. Jill's son is filled with anxiety about his mother's vulnerability and wishes her to be 'safe' in a 24-hour environment.*

This scenario brought about the realisation that formal carers may have conflicting opinions on the most appropriate course of action, that clients such as Jill have perspectives and informal support networks that can guide their clinical experiences, and that informal carers are sometimes overwhelmed by the task of balancing risk with uncertainty. In spite of this, decisions are often made as a result of the personalities involved and the team dynamics, making it easy to lose sight of the best

interests of the client. In this instance, the paternalistic concern over physical 'safety' couched in concern over diagnostic needs was given precedence to the ultimate psychosocial detriment of the client who died shortly after being moved into residential care. Her son reports that he is left with the over-whelming guilt that his mum died of a 'broken heart'. This, and many other encounters, influenced the research in many ways, and serves to illustrate my position as a clinician who believes that my practice shaped and conversely, was shaped by the research experience. This inter-relationship will be an implicit and explicit tenet of this thesis. For these reasons, a movement in focus occurred during this study from an emphasis on multidisplinary issues to more biographical, lived experiences of participants, which included but also transcended experiences of multidisciplinarity.

More recently, during the writing of the thesis, I became a carer of a severely and chronically mentally ill member of my family, thus creating a time delay in writing the thesis. This time delay generated both positive insights and difficulties in assimilating what essentially became a two-phase project, punctuated by a change of government, shifting policy agendas and professional approaches to the areas under study, as well as personal developments in terms of my experiences as both an informal carer and an increasingly experienced district nurse. This posed a serious challenge in terms of establishing that the thesis still had appropriateness and value in the academic and professional arenas. Decisions taken here were then reflected in the challenge of how to present the thesis in a transparent and clear way that acknowledged the developments and changes in public and professional arenas since

data collection and analysis. The decisions that were taken are outlined here and in the remainder of the thesis.

Aims of the study

- To observe and interpret relationships between individual and groups of chronically ill adults, informal carers and staff in a general hospital.
- To explore ways in which different professional groups define their own contributions and the contribution of other professional groups in meeting defined client needs in hospital settings.
- To interpret these definitions in the context of multiprofessional practice and its sociological, political and historical elements.
- To explore the lived experience of chronic illness within the context of the hospital culture.
- To extend the above aims to include similar investigations of, and comparisons with, lived experiences of chronic illness, multiprofessional responses and interfaces in a school setting.
- To assimilate findings from each setting to provide understanding of the meanings and experiences of living with chronic illness that may contribute to the development of generic approaches to caring for chronically ill people in health and education settings.

Definitions of terms

Because of the diverse ranges of organizations, client groups, and staff groups who were included in the study, it is necessary to outline definitions of terms that are referred to within the thesis:

- **A person with chronic illness,** in the context of this study, is a child or adult in receipt of formal care who has been chronically ill, or is expected to be ill for a period of greater than 3 months.
- A **carer** is considered to be a person who provides the major part of caregiving which has arisen as the result of emotional or family ties, rather than as a result of organizational responsibilities. The choice of this term does not indicate that carers are less 'expert' or knowledgeable about the care they give than a formally trained member of staff.
- **A professional staff member** is a person who is employed by an organization to deliver a service and has some form of professional training for their role.

Presentation of data

Quotes taken from data are presented throughout this thesis using the following format:

"Just how am I going to cope with it all when he gets home." (Joseph's wife, interview one, hospital sample*)*.

All data is anonymised, with a pseudonym given to each participant. As agreed with children and their families, only those photographs that do not show faces are included in the thesis.

An overview of the study

A detailed review of the literature and sampling decisions are provided in the following chapters, but it is relevant here to consider the care contexts of people chosen to be research participants at the time of commencing the study. Initial interest in multiprofessional practice led to an acknowledgement that it is clients with chronic, multiple needs and problems who require the input of the multi-professional team and who present the biggest challenge to all members of the team, both individually and collectively. It was anticipated that several diagnostic categories might have provided access to these issues; for example a person with multiple sclerosis might be expected to access services from a variety of professional groups over a long period of time. However, at the time of the launch of the study, the care of stroke patients became a major research priority both nationally and locally (Northern and Yorkshire Regional Health Authority Research Report, 1994). Previously regarded as an underdeveloped 'Cinderella' service, research into the care of stroke patients was an exciting way of making a contribution to a neglected area of study. More specifically, stroke patients have multiple needs and problems which are addressed by the whole range of professional staff in hospitals and in the community. The fact that a stroke is not necessarily life limiting meant that this diagnosis would allow me to carry out a longitudinal exploration of chronic illness. Links between

hospital staff and a project supervisor led me to use a General Hospital in the North East of England as the selection area for my sample group of stroke patients admitted to its wards. The hospital had the highest bed occupancy in the Northern Region for stroke patients at the commencement of this study in 1993-1994, and recognition of this fact led to an increase in health promotion activity in the area and the classification of stroke patients as a major research priority group within the region.

It was in this context that the perspectives of the research participants emerged and the research questions began to be articulated formally. What emerged as important was an exploration of the meanings of clients' experiences within the historical, political, and ideological context of current services for chronically ill people and their families. Those experiences were influenced on a daily basis by the medicalised, acute, fragmented approach to their care. It became clear that specific, specialised rehabilitation strategies had little significance to patients who were attempting to create meaning from receiving formal and informal care and who were trying to assimilate multiple needs and problems into their ordinary lives and relationships over a long period of time.

This shift in focus from a diagnostically defined, medicalised set of problems to more generic issues led to the development of the second phase of the study. A literature and geographical search was made for a multiprofessional setting in which people with multiple needs and problems are served within a context that offered a contrast to the emphasis on acute medical and physical rehabilitation. Again, links between school staff and a project supervisor led me to the selection of a special school in the Northern region within which to base my observations. The special

school claimed an explicit rejection of a medical model of care and, at the start of the study, had made attempts to create a multiprofessional organisation in which educational, emotional and spiritual development has precedence over physical therapies. The school catered for physically disabled children between 3 and 19 years old and many of the children have diagnoses that may or may not be life limiting and generate multiple chronic needs and problems. The theoretical links between each setting are explored more fully in chapter four and focus on illuminating commonalities and differences between diagnostic groups of different ages being cared for within different organisations, and the shared experiential and emotional aspects of living with chronic illness from the view-points of adults, children and their carers.

Within this context, the guiding principles, aims and outcomes are identified below.

Guiding Principles

This exploratory, inductive study drew from a variety of principles, some of which were followed from the start and some of which emerged as the research evolved.

- It is exploratory research which begins with the question 'what is happening here?' and does not have pre-determined questions.
- It involves exploration of the key concepts and models that underpin lived experiences.
- It will increase understanding of the ideological, political, and historical factors and how they affect perceptions and experiences of health care and educational practice.
- It will lead to increased knowledge and awareness about living with chronic illness rather than attempt to predict and generalize.
- It will lead to critical analysis and discussion of issues.
- It will ensure anonymity and confidentiality and will protect research participants by omitting aspects of findings that may be used against them.
- Data will be collected in a way that acknowledges the different voices in the research and the potential power differential between them: the anonymous voices of the research participants; the collective voice of the research team who guided and influenced me at every stage; the individual voice of myself as a female researcher working in clinical practice and more recently as an experienced district nurse and carer.

Sequence of research

The study was completed in two phases; phase one was carried out in a hospital setting involving stroke patients and their formal and informal carers, phase two was carried out in a special school setting involving physically disabled children, their formal and informal carers. For clarity, the two phases are presented here as discreet entities although, for reasons discussed later, the phases overlapped in real time and had influence on each other.

Date	**Activity**
October 1993-May 1994	Methodological and theoretical literature search. Gatekeeper contacts. Application for hospital Ethics Committee approval. Development of observation schedule.
June 1994 - November 1994	**Hospital setting:** Observation of client daily hospital life (n=4). Interviews with clients (n=9) and informal carers (n=8). Data analysis.
December 1994 - May 1995	Development and dissemination of questionnaire to staff working with stroke patients (n=31). Data analysis.
April 1995 - January 1996	**Special school setting:** Observation of client daily school life (n=20). Interviews with clients (n=11) and informal carers (n=12). Data analysis.
February 1996 – May 1996	Development and dissemination of questionnaire to staff working in special schools (n=35). Data analysis.
April 1996 - Present	Writing up. Dissemination.

Table 1: Sequence of research (n= sample size)

Hospital sample group

The purpose of phase one was to address the aims outlined on page 5 in the hospital settings using data collected from stroke patients and their formal and informal carers. The sample group was selected initially from four general medical wards in a general hospital and subsequently from ten general hospitals in the Northern Region. Semi-participant observation was carried out with four stroke patients and non - structured interviews were carried out with nine patients and eight informal carers. The observation and interview data was used to develop an open-ended questionnaire which was distributed to 31 staff currently working with stroke patients in ten general hospitals in the Northern Region.

Special school sample group

The purpose of data collection in the special school was to explore the aims outlined earlier in a special school setting which caters for children aged between 2 and 19 who have physical disabilities and learning difficulties associated with physical disability. Data collection was then extended to include 10 special schools and mainstream schools with special needs units within Newcastle upon Tyne. Observation was carried out with 20 children. Interviews were carried out with 14 of those children and 12 informal carers. Photography was used with 9 children in order to facilitate their engagement with the research process. The observation and interview data was used to develop a questionnaire which was completed by 36 staff working with children with multiple needs.

Outcomes of the study

For various reasons involving family and career, progress on the thesis was delayed for a period of 3 years. Because of the length of this delay, it was felt necessary to re-evaluate the appropriateness and value of the thesis in the current academic and professional context. It is relevant to outline the decisions taken here since they are reflected in the presentation of the data.

It was anticipated that this study will continue to inform knowledge on several aspects of research into the chronic illness trajectory, namely, methods of data collection with vulnerable clients, practitioner-research, multiple pathology, the expert patient, chronicity, and specialist care outcomes.

- **Methods of data collection**

At the time the study was carried out, some of the methods and methodologies used were innovative and still in the developmental stage, particularly the use of photography (Davies, 1997). Literature reviews show that since this data collection these methods have become more widely used, indicating that the study now converges with current methods. In particular, the voice of children is only recently being acknowledged in research and policy alike (Sartain, 2000). This study viewed children as competent interpreters of their worlds and demonstrated the ability of children to fully engage in the research process. Research that examines the lived experience of vulnerable people has become more established (Burton, 2000), although conclusions remain tentative and less influential upon policy and practice than more quantitative methods of enquiry. Chapter three presents the ongoing

debate about qualitative methodology and its place in service development. Dissemination of this study will contribute to knowledge of method and methodologies designed to give a voice to chronically ill and disabled people.

- **Practitioner research**

A second area of interest and innovation is the intention to integrate an exploration of my own professional experience in the context of findings and data analysis. From the outset, the research acknowledged and examined the fact that I was and am a healthcare professional whose work is influenced by, and has an influence on, data collection and analysis. This approach was note-worthy at the time the study commenced and was in its infancy at the time of data collection but has since become well established in the arena of practice development and practice-based research (Reed & Procter, 1995). However, it remains uncommon for a practitioner to undertake such a large-scale study with academic funding while formally acknowledging and examining personal experience of service provision to inform the direction of the study. Exploration of my own experience and the reflexive nature of the research are discussed in chapter three and contributes to an understanding of the issues facing practitioner-researchers.

- **Multiple pathology**

Within this study, data were taken from specific client groups with definable illnesses or problems, namely stroke and various childhood disabilities including cystic fibrosis and muscular dystrophy. At the time of data collection, enquiries into

aspects of chronic illness were diagnostically specific in their approach (McLean et al 1991). Initial analysis of data was therefore carried out within the context of specific political and practical developments in the area of stroke care and special education. However, the political and professional shift towards a more generic approach to chronic illness (for example National Service Framework for Older People, 2001) is mirrored by the analysis of findings in this study that demonstrated a commonality in processes of adapting to chronic illness. One of the most interesting findings was that most of the clients had multiple pathologies and required multiple levels of service provision as a result. For example, a person suffering a stroke might also have chronic heart disease or diabetes; a child with cerebral palsy might also have asthma. The ways in which families coped with multiple problems and needs became the main focus of interest within the study, particularly in terms of the ways in which the uncertainty and unpredictability of these needs were managed within the context of relationships between families and service providers. Analysis of the psycho-social processes involved in managing uncertainty contributes to an area that is currently in its infancy within the literature. Exploration of these processes are presented in chapters 7& 8.

- **The expert patient**

The recent wide ranging document 'The Expert Patient' (DoH, 2001) acknowledges that people with any chronic illness may share a number of problems and strategies for dealing with those problems. However, it remains diagnostically specific and firmly focused on bio-physical standards of care in its discussions on the approaches

formal carers should take when caring for clients. In its discussion on common requirements of people with chronic illness (The Expert Patient, DoH, 2001, p.17), it does not acknowledge multiple pathology and the management of multiple symptoms as being a consideration. This contrasts with findings in this study in which families might be in receipt of specialist stroke care, but would often be left to co-ordinate and prioritise that care in the context of other treatments and service provision. Families were often very successful at this high level of co-ordination, a fact that was not acknowledged explicitly by service providers or in policies such as the Expert Patient document. Others were not so successful, with clear consequences to their health and well being. This is explored in chapter 8 of the thesis. The implications of this for service providers is discussed in chapter 9.

- **Managing chronicity**

In the time since initial analysis of data there have been changes in the approach to chronic illness at both political and practical levels, which are addressed in the literature review (chapter 2). These changes include the shift from Conservative to Labour Government which brought with it a wholesale reanalysis of the importance given to formal and informal care in the community (the emergence of Primary Healthcare Trusts and the introduction of clinical governance being the most obvious changes), as well as a 10 year action plan to improve hospital care (The NHS Plan, DoH, 2000). A finding of this study focused on how the life experiences of children with chronic illness were altered as a result of whether treatment, maintenance of health, or social and academic development was given precedence by their informal

and formal carers. It appears that the priority given to each of these appears to depend largely on the prevailing political and academic climate (Kenworthy & Whittaker, 2000) which at the time focused very much on allowing children with physical disabilities the same access to services and mainstream education as their non-disabled peers (Aspis, 2001). In the intervening time since data collection there has been increasing interest by policy makers and health service researchers in literature produced by the disability movement (Barton, 2001). This political shift is mirrored in this study which found that disabled people did not object to being treated differently from non-disabled people as long as they were given services and care that enabled them to live life as they wanted. For example, the children and families in this study were very positive about the services they received in special education as this enabled them to become equipped for life after special schooling. In contrast to this, stroke patients suffering associated illness such as peripheral vascular disease, were given short episodes of care to deal with acute exacerbation of the condition, but service provision did little to manage the chronic needs resulting from their multiple illnesses. The debate over acute/long-term management of chronic illness remains highly pertinent in the current arena and the discussion in chapter 9 will contribute to knowledge of the illness trajectory from the point of view of people dealing with chronic illness throughout the life span.

- **Specialist care outcomes**

Another focus of this study was the ways in which service providers worked with families and with each other to provide care. At the time of data collection, 'multi-

professional working' was the focus of intense political and professional interest with analysis focusing on ways in which coordination and management decisions where taken in cases where several professional groups were involved. More recently, policies such as 'Working Together-Securing a Quality Workforce for the NHS' (DoH, 1999), focus on improving relationships between organisations and groups to improve performance. The findings of this study focus on the quality of relationships between clients, families and formal carers and ways in which service providers work together to help the client cope with diagnosis and the uncertainty of prognosis, areas which are not explicitly recognised in the political or professional arena. This would necessarily call for service providers to have specialist knowledge and training in the chronic illness trajectory, representing a shift from more traditional diagnostic, acute specialist services. Exploration of this theme in chapter 9 gives a practice development focus to the thesis and outlines the ways in which professional staff could respond to the generic needs of chronically ill people and their families at each stage of the illness trajectory.

Presentation of the thesis

This thesis is presented in 9 inter-related chapters that discuss the literature review, methodology and methods, findings and their implications for practice:

Chapter 2 –The literature review

The literature review interrogates the literature with regard to two main features; firstly, the ideological, political, historical, practical and experiential dimensions of chronic illness and secondly, ways of knowing about chronic illness. What emerges from this analysis is a view of policy and ideological approaches to chronic illness that carries inherent contradictions about the health and social care of chronically ill people. Analysis reveals a strong commitment to improving national standards of care for people with enduring illnesses such as diabetes and heart disease via National Service Frameworks (NSFs). However, the bio-physical emphasis of these standards, set alongside the wider curative, rehabilitative model of Western health care, appears to give little recognition to the temporal, deteriorating nature of many chronic illnesses, or to the clinical responses to these. A large body of research into diagnostic-specific understanding of chronic illness exists which contrasts with a more recent 'non-categorical' approach that focuses on commonalities and processes of adaptation, normalisation and coping.

This analysis guided the focus and direction of this study in several ways concerned with a) the exploration of commonalities and differences in the experience of specific chronic illnesses, b) the importance of representing the temporal element

of chronic illness, and c) exploration of the interface between people with chronic illness and their formal and informal care-givers

Chapter 3 – The Theoretical Framework

This chapter presents a rationale for the adoption of a qualitative paradigm that draws upon humanistic tenets in order to develop an organisational framework that makes explicit the author's own beliefs and views about the world. Symbolic interactionism are adopted as interpretive tools, and grounded theory is used in order to confer structure to data analysis and theory generation. Ethnography and phenomenology initially informed research decisions but were discarded for reasons discussed in this chapter.

Trustworthiness is discussed in relation to rigour, confirmability and the ability of the reader to trace a 'decision trail' throughout the thesis is identified as a prime concern in the development of this study.

Chapter 4 – Selecting and accessing a sample

The selection of sample groups was influenced and informed by both pre-determined research decisions, and the demands of theoretical sampling, in which initial data analysis guided further sampling decisions. Samples were identified and accessed through gatekeepers in two settings, firstly, a general hospital in the North of England, and a special school in Newcastle.

In the hospital setting, data were collected from 12 stroke patients, 10 informal carers, and 31 formal carers working in hospital settings. In the special

school setting, data were collected from 17 chronically ill children, 16 informal carers, and 37 formal carers working in special educational settings. The geographical location of each sample and participation issues are discussed in relation to ethical integrity, ongoing informed consent, and the termination of the researcher/participant relationship.

Chapter 5 – Data collection

Three methods of data collection were employed in this study, namely, semi-participant observation, unstructured interviews, and qualitative questionnaires. Methodological triangulation is discussed and each method is discussed in terms of the completeness and confirmation it conferred to the study as a whole.

Data were collected from stroke patients using observation and interviews carried out longitudinally that were designed to capture the long-term experience of chronicity, and its daily management both in hospital and at home. Interviews were carried out with informal carers and provided insight into the process issues concerned with becoming a carer in a sudden, unplanned manner. Questionnaire data provided the opportunity to explore previous data with formal carers working in a variety of settings to check for commonalities and differences between settings.

The second phase of data collection used the same techniques with children with chronic illness, their parents, and formal carers. Interviews carried out with children were based on photographs taken by the children themselves, with the intention of encouraging engagement with the research process and a reduction in the potential power balance between a sick child and an unfamiliar adult.

Chapter 6 – Data analysis

The intellectual and physical processes of data analysis are discussed in this chapter. Grounded theory informed the process of constant comparison of data from which themes and categories began to emerge and were tested against subsequent data. The process of analysing three types of data was assisted using memos and diagramming. Examples of each are presented in this chapter, via a process of identifying the social processes for coping with chronicity that contribute to the emergent theory of embracing uncertainty.

Chapter 7 – Dimensions of uncertainty

Adaptation to uncertainty is presented as the core social process identified in this study. This chapter presents the dimensions of uncertainty that contribute to both a background, sustained level of uncertainty throughout the illness trajectory and periods of heightened uncertainty at various stages over the biography of the person with chronic illness.

The dimensions are presented in the context of an unpredictable illness trajectory that begins at the onset of symptoms, though diagnosis and ends only with death. A sustained feeling of uncertainty is experienced across this trajectory that is heightened as a result of acute episodes, unpredictable needs, and unpredictable environments. Unpredictability and loss of control are major factors in the experience of uncertainty and are influenced by fluctuating needs that may require hospital admission. Within this, people with chronic illness and their families experience uncertainty, unpredictability and loss of control regarding their social,

physical and organisational environment. Evidence for these themes are presented using quotes taken from interviews and questionnaires, memos written during observation, and impressions taken from post-contact notes.

Chapter 8 – Management of uncertainty at the interface between chronically ill people, their carers and professional staff

This chapter describes the changing nature of relationships between chronically ill participants, their carers and professional staff. Three inter-related processes are elucidated that were concerned with understanding, accepting, and adapting to the uncertainty inherent in the illness trajectory. These processes were temporal and were firmly rooted in the relationships between the chronically ill person, their family, and the professional staff who came together to meet their needs.

Chapter 9 – Implications and reflections: An emerging theory of uncertainty management

This chapter revisits the pivotal questions posed in the literature review about the nature of chronic illness and the ways of exploring the lived experience of chronic illness. Symbolic interactionism is presented as an effective tool for exploring the interactions between patients, families and professional staff. The merging formal theory is interrogated in relation to the criteria for theory generation outlined by Strauss (1987). Limitations of the current study are identified in terms of methodology and method. Analysis is then made of the ways in which the strategies outlined earlier contribute to an emerging theory of adapting to chronicity and

embracing uncertainty throughout the trajectory. It explores the implications for formal caregivers working in a variety of settings with chronically ill people. This chapter explores current understanding of uncertainty in chronic illness and outlines the ways in which this thesis contributes to knowledge about the lived experience of uncertainty across diagnostic and age categories. Finally, future practice development and research ideas are discussed.

Chapter 2

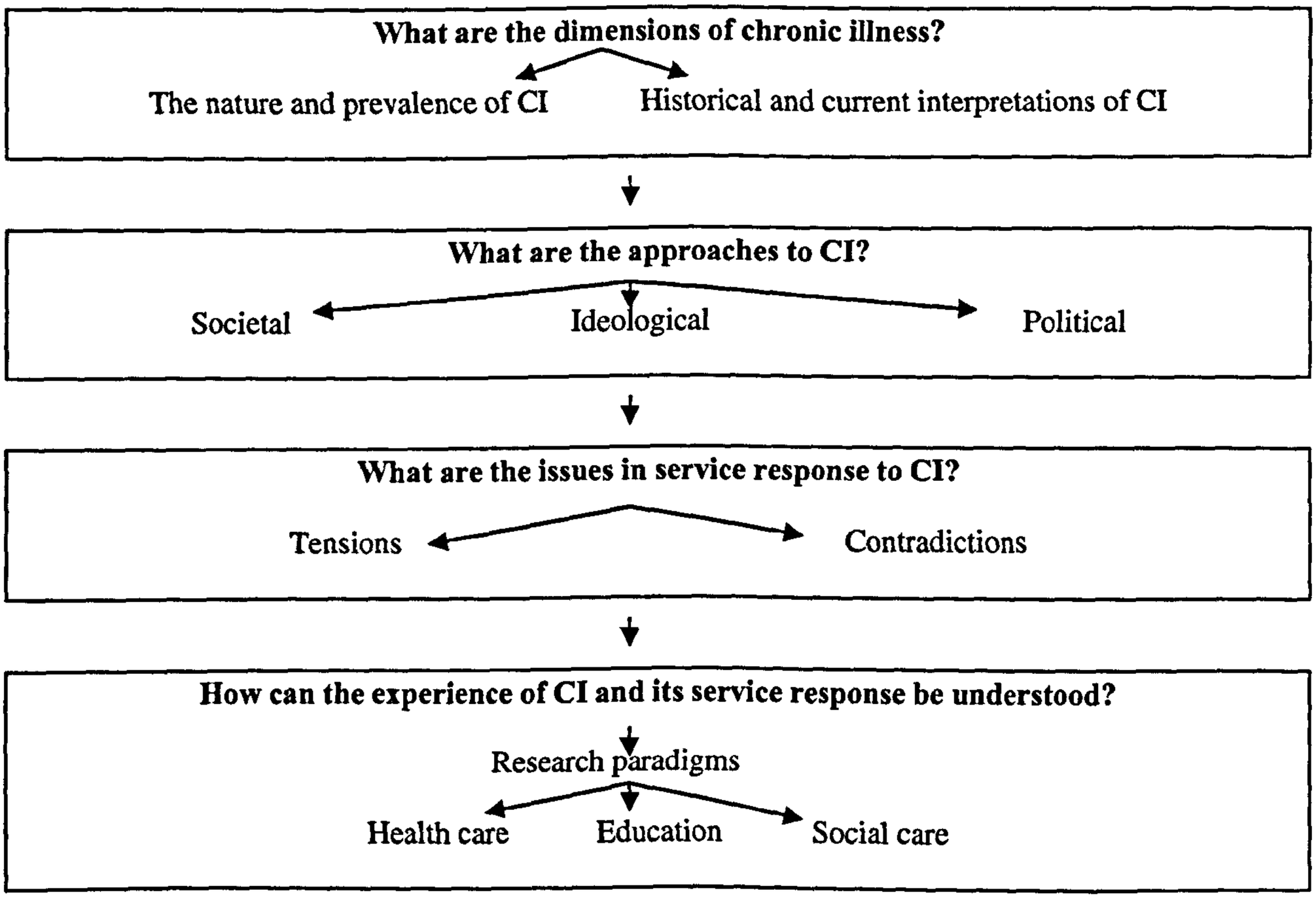
Literature review:

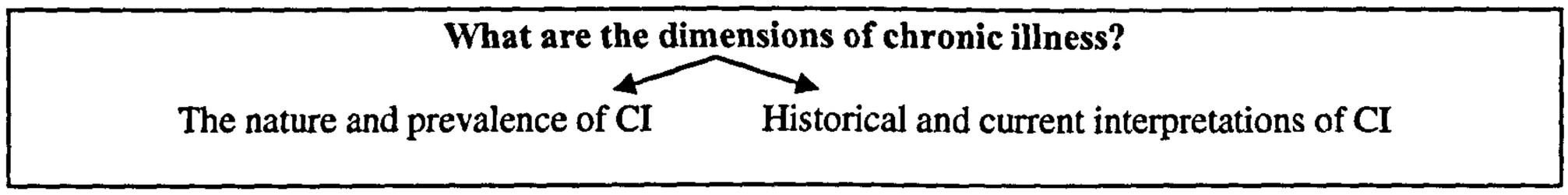
Dimensions of chronic illness

Introduction

This review presents an analysis of literature that informed this research concerning the three key participants, namely, the child or adult with chronic illness, their family carers, and professional staff working in health and educational settings. The review draws on a range of literature from social policy, sociology, education, psychology, nursing and medicine. The wide-ranging issues are presented as a series of fundamental questions (figure 1) about the nature of chronic illness (CI). These questions provide focus for the literature review and are revisited in the final chapter in relation to the findings of the thesis.

***Figure 1*: Overview of the literature**





Definitions of chronic illness

Attempts to define chronic illness are most commonly located in its temporal nature (Eiser, 1993), and its inability to be medically 'cured' (Payne and Ellis-Hill, 2001). These definitions are reflective of current professional responses to chronic illness that focus on increasingly advanced technological interventions and rehabilitation therapies located within a discourse of recovery. The World Health Organisation (2004) defines chronic conditions as;

"*health problems that require ongoing management over a period of years or decades.*"

The difficulties in defining CI rest on the fact that chronic illnesses encompass such as broad range of health concerns, from noncommunicable diseases such as cancers and diabetes, and infectious diseases such as HIV, to mental disorders such as depression and schizophrenia (WHO, 2004). These illnesses differ in aetiology, stability and predictability as well as their management complexity and the daily restrictions they place on life (Eiser, 1993). This diversity of experiences appears to have led to difficulties in categorising the commonalities and differences in the representations of CI, and challenges in teasing out the defining nature of CI. To demonstrate this complexity, Rolland (1989) contends that chronic illnesses vary in their stability and predictability and divides the disease process into three main

forms, namely a constant course, relapsing or episodic, and progressively severe. For example, children with juvenile rheumatoid arthritis can be expected to have relatively stable, if poor, health while leukaemia and asthma can cause unpredictable, sudden reduction in well-being (Eiser, 1993). Some chronic diseases such as cystic fibrosis and muscular dystrophy are degenerative and life limiting while others, such as diabetes and some cancers, respond well to medical treatments that change the nature of the disease from life threatening to chronic. The layers of complexity are further underlined by writers such as Lyons et al (1995) who suggest that chronic illnesses vary along a continuum of treatment complexity, technological dependency and responsibility for its management and in the varied responses of social networks to differing diagnoses (Thorne, 1993).

Despite these attempts to analyse the definitive nature of CI, predominantly from British and North American authors, the emerging picture is of confusion and contradictions in societal and service responses to chronic need. Nolan et al (1996) refer to the 'bedlam' vocabulary in which terms have been defined in numerous, conflicting ways, with little attention paid to shared understandings. This is exemplified by the terminologies of chronic illness and disability; chronic illness often results in disability, and disabled people sometimes, but not always, have a chronic illness (Oliver, 1989; Priestley, 2001). A growing body of literature now challenges medicalised, individualised definitions of disability and illness (Bickenbach et al, 1999) that fail to take into account the social and environmental causes of disability. However, the substantive literature on chronic illness has little in

common with these debates and prefers to locate the experience of CI firmly within individualistic, diagnostic-specific, recovery orientated frameworks (Bury, 1988).

Overall, it seems that although the study of 'chronic illness' has attracted much attention over many years both in the professional and policy arenas (Anderson and Bury, 1988; Corbin and Strauss, 1988; Thorne and Paterson, 2000, Charmaz, 2000), the challenge of defining the exact nature of chronic illness continues to pose unanswered questions about its prevalence, its process elements, and clinical care responses to these. Verbrugge and Jette (1994) call for the development of a common conceptual scheme on which research, policy and clinical care can be built. With this in mind, this thesis suggests a pathway of care (chapter 9) for people with chronic illnesses that is located within the illness trajectory from pre-diagnosis to death, rather than within diagnostically specific parameters.

Prevalence of chronic illness

In spite of semantic and philosophical difficulties in defining CI, the emerging world-wide picture is of an increase in life-expectancy, as a result of medical, social and pharmacological advances, coupled with an unrelenting increase in chronic illness. Attempts to quantify the prevalence of chronic illness in Great Britain rely on both predictive (Thompson, 2002) and retrospective (Lovett et al, 2003) studies of the incidence of specific, diagnosed conditions and on the resulting levels of disability and handicap (De Haan, 1993; Bickenbach et al, 1999). Estimates from various geographical areas suggest that between 1 in 10 and 5 in 10 people will experience a chronic illness at some point in their lives, the leading causes being

heart disease, stroke, cancer, and depression (WHO, 2004), while British figures indicate that 10-15% of children under 16 years of age are affected by chronic conditions (Eiser, 1993). The World Health Organisation predicts that chronic illnesses will become the main worldwide cause of death and disability by the year 2020 (Epping-Jordan, 2001). Many authors (Corbin and Strauss, 1992; McBride, 1993; Nolan et al, 1996, Quin, 1996, Payne and Ellis-Hill, 2001) suggest that CI represents one of the major challenges to health and welfare systems in the developing world, but suggest that our understanding of chronic illness is 'sparse and underdeveloped' (Nolan et al, 1996, p.135).

One reason for this lack of understanding lies in the way in which traditional epidemiological studies of CI are conducted. British health statistics and epidemiological studies categorise morbidity and mortality rates in relation to specific diagnoses and their disability and handicap levels and give a static, rather than a more complex, temporal view of CI. For example, the Stroke Association (1994) states that 350 000 people in the UK are directly affected by stroke, and that each year 100 000 people will suffer a first stroke, while cystic fibrosis is the most common, life-threatening inherited disease in the United Kingdom affecting approximately 1:2500 live births (Lewis, 2000). Statistics show the likelihood of being disabled as a result of these diseases at the time of any particular study but are unable to give a more temporal view of chronicity, in terms of how long a person might expect to live with a stroke and the levels of disability and handicap as they fluctuate over time.

A second reason for the difficulty in categorising and measuring CI is that medical advances are increasing pace rapidly and life expectancy across all diagnostic groups has increased, and will continue to increase over time (WHO, 2004). The emerging international and national picture is of growing numbers of people being kept alive by medical and technological advances and living a life characterised by multiple, complex needs that fluctuate over time. What is less clear is the extent to which health can be restored and maintained through provision of appropriate and effective services. The resultant difficulties in defining, understanding and meeting the needs of such a disparate group of people is expressed by Burchardt (p. 645, 2000) who states;

"Failing to distinguish the different disability trajectories people follow has led to policies which marginalize disabled people and are costly to the state."

The apparent lack of shared perspectives and in the case of the disability standpoint, politicised territoriality, between the substantive bodies of literature on CI leads to professional and clinical challenges in giving appropriate, timely care to those who require it (Nolan et al, 1996). The ways in which these challenges have been addressed over the years are the subject of the following section which analyses the various historical approaches to addressing the needs of people with enduring disease and disability.

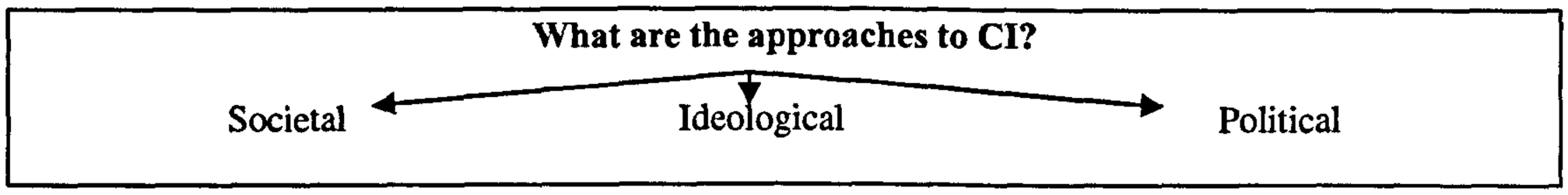
Historical dimensions of chronic illness

Historically, approaches to caring for chronically ill children and adults have been firmly located within a personal tragedy model, in which the person was viewed as economically unproductive (Finkelstein, 1993) and therefore needed to be hidden away in institutions, such as TB wards, designed to medicalise and problematise the illness or disability (Marks, 1999). The collective concept of health seen in the early twentieth century focused on basic public health measures and the relief of poverty; people who found themselves chronically ill or disabled were incarcerated for long periods of their lives, hidden away within a powerful rhetoric of cure or care provision for the 'weak' and 'needy' (Hevey, 1993). State control of health care and paternalistic approaches to illness were brought into question by a powerful critique of the welfare state by the Conservative right in the 1980s that promoted both the marketisation of health care, and the active influence of service users on the delivery of social and health care (Ham, 1999). This endorsed the idea of chronically ill people as consumers who were able to define their own needs and choose aspects of their care, thus challenging the idea of chronically sick people as passive recipients of a benevolent state system.

Traditionally, the question of how best to meet the complex multiple needs of chronically ill people appears to be answered within the discourse of institutionalisation, rehabilitation, recovery, and cure. This has long been carried out within a system of medical dominance in which doctors control key resources such as expertise and knowledge that is promoted by Western approaches to health and social care (Longino, 1998). This Western approach is built on beliefs about

"body-mind dualism, physical reductionism, the mechanical analogy, specific aetiology, and the body as the appropriate focus of regimen and control." (Longino, 1998, p. 101).

Both politically and ideologically it seems that this medical model is coming under increasing attack; a shift is occurring back to an emphasis on social and environmental influences on health. This followed the widely acknowledged acceptance that the key determinants of health are factors such as housing, environmental pollution, diet and smoking (DoH, 1999, Scott and West, 2001). Attempts to influence these factors are underpinned by the establishment of Health Action Zones and local Health Improvement Programmes intended to address the effects of poverty on health. Labour's 10 year plan (DoH, 1999) is based on a commitment to make the NHS more patient-centred, with the emphasis firmly on promoting self-reliance, through initiatives such as the Expert Patient programme (DoH, 2001). The commitment to a more holistic approach to health has brought focus to a previously neglected public health service with the aims of disease prevention and health promotion via the development of a strong primary health sector (DoH, 1992, 1999). The ways in which these new agendas influence the health and social care of chronically ill people is the subject of the following section.



Societal, ideological and political dimensions of chronic illness

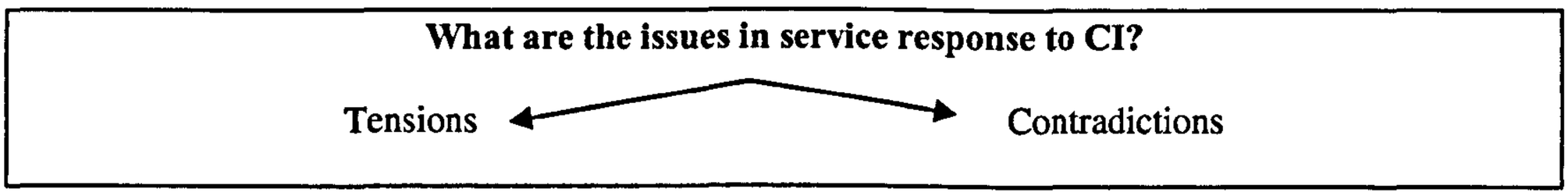
The competition for resources between people with acute, curable needs, and those with enduring health problems results in what the World Health Organisation (2004) refer to as the "Failure of Health Care" to provide for the growing numbers of people with chronic illness. The WHO (2004) attribute this failure to the fragmented, acute organisation of care provision that offers only sporadic follow up, the lack of emphasis on the patient's experience and role in management, the lack of investment in community services, and the prevention of chronic conditions. Current policy in Britain encapsulate New Labour's political emphasis on a holistic community based approach to health, commonly termed as the "Third way". (Connelly, 1999). The recent political and practical emphasis on investments in community care and prevention of chronic illnesses lie at the heart of recent policies such as 'Saving lives – Our healthier nation' (DoH, 1999).

A predominant approach to evaluating these macro level health and social policies rely on evaluation of the ways in which policies compare with other systems and strategies that are guided by such perspectives as feminism, postmodernism and Marxism (Scott and West, 2001). The complex debates originating from these perspectives are firmly rooted in cause (addressed within the rhetoric of illness prevention and health improvement) and treatment (located within the rhetoric of cure) (Ham, 1999), leaving unanswered questions about policy and service provision

for those with incurable, enduring needs. In particular, New Labour's apparent shift in emphasis from cure to prevention appears to leave little room for development of services for people who are already chronically ill, people for whom either prevention or a cure has little purpose.

Recent conceptual analyses of chronicity have been located in controversial arguments from Disability rights lobbyists who challenge the medicalised, individualised approach which fail to classify an illness as chronic; to do so would be to implicitly acknowledge the failure of medicine to provide a cure. Harrison (1993) asserts that within the medical model, people with CI *"had failed to benefit from medical treatment and were therefore a problem, usually best left to themselves or to others to cope with."* (p.211). This is illustrated in the case of stroke care; although it is commonly viewed as a chronic illness, service providers refer to the 'stroke recovery' trajectory, thus implying a move towards cure (Burton, 2000). This contrasts with evidence that as many as two thirds of all stroke survivors have residual functional and physical difficulties for many years following a stroke (Grant and Davis, 1997).

Awareness of the tension between acute and chronic management of care highlights one of a series of contradictions in political and ideological approaches to caring for people with enduring health needs. These contradictions and tensions provided contextual understanding of the experiences of participants in this study and are outlined here in relation to chronicity and professional responses to chronic needs.



Chronicity

An important element of the understanding of chronic illness over the life-course is an appreciation of the temporal nature of chronic illness. Chronic illnesses are characterised by their enduring, long-term nature that is not simply a singular acute event but a set of complex physical, emotional, and psychosocial processes that develop over time. The experience of chronicity is described by Zola (1981, p. 143):

> *"Our daily living is not filled with dramatic accomplishments but with mundane ones. And most of all, our physical difficulties are not temporary ones to overcome once-and-for-all but ones we must face again and again for the rest of our lives. That's what chronic means."*

A major contradiction apparent in analysis of current health and social policy lies in the specific ongoing health care of chronically ill people, delivered within a system designed to meet acute, curable needs. It has been argued by many authors that health and social care have traditionally been oriented to short-term acute care, rather than to the ongoing, long-term needs of people with chronic illnesses. Some authors stress the problematic nature of offering chronically ill people a service that is structured around an acute model of care (Quin, 1996, Thorne et al, 2000). For example, Gibson and Kenrick (1998) drew a British sample of 9 patients who had had vascular surgery in the past 18 months. Using a phenomenological approach, they found that the acute style of management of peripheral vascular disease did not

correspond with the chronic nature of this disease and led to unrealistic expectations on the patient's part, giving rise to feelings of powerlessness.

The failings of the acute model have recently been addressed at policy level with the introduction of National Service Frameworks (NSFs), (Department of Health, 2001), initiated in 2003 which identify explicit long-term goals for services providing care for older people, people with diabetes, coronary heart disease, mental health and more recently, children. The advent of NSFs involves implementing national standards, against which measurement of progress can be carried out, all of which focus largely on bio-physical monitoring of ongoing diseases and on offering health prevention measures such as smoking cessation (Piper, 2000).

The standards are closely tied to the current agenda for health improvement, which some authors suggest is not necessarily congruent with the needs of chronically sick children and adults (Arnfield, 2001). In particular, they fail to fully acknowledge the chronicity inherent in enduring illnesses and instead offer an acute, sporadic management style for chronic disease. The pressure on practitioners to meet these standards coupled with the focus on health promotion and prevention appears to emphasise the locus of individual responsibility for maintenance of health; this strongly contrasts with the current rhetoric of addressing societal and environmental causes of illness and disability. This individual locus of responsibility is expressed in interventions such as smoking cessation programmes and influenza vaccination strategies. Some authors suggest this locus contributes to a culture of 'self-blame' when a 'preventable' chronic illness occurs (Taussig, 1992, Lee-Treweek, 2001). In addition, some authors criticise the Expert Patient programme (in which chronically

ill people are encouraged to self-manage their condition) on the basis of tensions between its competing requirements of compliance and self-reliance (Thorne et al, 2000; Wilson, 2001). The continuing rhetoric of cure and bio-physical rehabilitation for chronically ill people, alongside a health promotion agenda designed to narrow the health inequalities gap in Britain, appears to give chronically ill people conflicting messages about the social, political and ideological meanings behind their illnesses, located within a discourse of individual failure to maintain health, and family responsibility for providing care unsupported by the state. This is powerfully, although not solely, expressed in terms of the disability critique of the ways in which chronically ill people are portrayed in health and social policies.

On the one hand, the Disability Rights Act (DoH, 1986) has led to decreased marginalisation and gives chronically ill people increasing access to work and social opportunities. Using frameworks of 'claiming' and 'interrogating', disabled writers and activists are now challenging the disabling social order and social relations that construct disability and elements of chronic illness in terms of individual and medical solutions (Barton, 2001). This sends the message that chronically ill people have a valuable role to play in society. This contrasts with an increasingly technology based health care system, often financially reliant on charities, that focus on finding a cure, located within a context that includes *"the threats of genetic engineering, selective abortion, non-resuscitation policies, health care rationing and euthanasia"* (Oliver, 2001, p. 158). Oliver suggests that these medical responses to chronic illness and disability send a powerful and destructive message about the value of life lived by a chronically ill person. The apparent clash of paradigms

between the rights of ill people to have their needs met over a life-time, and the Western pursuit of health at all costs appears to leave unanswered questions about the ways in which service providers can work with chronically ill people to enhance their lives (Wilson, 2001). The longitudinal nature of the research presented in this thesis allowed for a temporal picture to emerge of the experience of CI that captured the ways in which the needs of participants fluctuated over time, and the extent to which service responses were able, or unable, to accommodate these fluctuations.

The political and practical responses to enduring needs are discussed in the following sections that outline the contradictions and tensions in providing institutional and community based care, and analyses the rhetoric of rehabilitation and multi-disciplinary teamwork in relation to finding meaningful, workable solutions to chronic needs.

Special services for special people

The political and practical emphasis on 'community care' (NHS and Community Care Act, 1990; Working for Patients, 1989b; Carers (Recognition and Services) Act, 1995) represents a challenge to voluntary and statutory services to work more closely with the aim of postponing or reversing the need for institutional care. Political and professional expectations are of independent living supported by family and community based care for people with enduring needs (Parker, 1994). In practice, this rhetoric is set against limited resources and an institutional based approach to chronic needs, for example, in the provision of special schools or residential and

nursing homes for people whose needs are enduring and complex and who for one reason or another cannot be maintained in their own homes (Malin et al, 2002).

At first glance, there is little academic, political or professional dialogue between the substantive bodies of knowledge and practice concerning different diagnostic and age groups of chronically ill people, for example, elderly care and special education. However, the debates have much commonality in regard to the tensions of providing "*special places for special people*" (Oliver, 2001, p. 158) within an evolving context of independent, family based living and equally important competition for scarce resources. These tensions are demonstrated most strongly in the literature on special education. A dominant topic within literature on children with CI is that of 'integration' in which the competing 'rights' of a child with chronic illness are debated in terms of a right to specialised attention to their individual needs balanced against the right to be integrated into a main-stream educational system in which they do not experience discrimination (Swain, 1993). The rhetoric of inclusion is not matched by a significant reduction in the number of children taught in special schools; In England in 1985, there were 100 hospital schools with 4485 pupils, and 1429 special schools with 110262 students. Ten years later, these figures had fallen to 31 hospital schools with 228 pupils and 1292 special schools with 95271 students (Department of Health, 1996). The largest group of special schools cater for moderate and severe learning difficulties, emotional and behavioural difficulties (Ofsted, 1999) and smaller numbers cater for pupils with sight and hearing impairment, physical disability, language and communication problems and autism. Oliver (1993) discusses the 'medical hegemony' still evident in special education in

which medical need dominates educational need. This, he believes, contributes to the acceptance of the sick role and is consistent with the personal tragedy model of CI and disability in which children are taken out of class for therapy and operations are scheduled according to hospital schedules rather than educational programmes.

Similar tensions have been identified in attempts to meet the needs of adolescents leaving special education. Madden (1993) explored the implications of the Disabled Persons Act (1986) with 50 young people with severe learning difficulties during this transitional period. Through a series of qualitative observation and interviews, he concluded that the rhetoric of rights, responsibilities, aspirations and opportunities was, in practice applied by service providers using 'half-baked ideas of what is a desirable adulthood' (p.14) that failed to engage the young person with their own assessment and categorised needs to match available resources. For example, if the only resources available were day-centres, then the young people were categorised as 'needing' day care. This mirrors findings by Clarke (1995) that demonstrated how needs were defined by what resources were available for people with dementia.

The debate about special education highlights tensions found across the board in considerations of ways of allowing chronically sick children and adults the right to live independent, non-segregated lives with their families, while at the same time attempting to 'fit' into institutional and organisational contexts that struggle to meet their complex, enduring needs. Political and practical responses to these tensions are framed in discussions of 'community care', the subject of the following section.

Community care

The emphasis on community based care has its origins in the Labour government's commitment to social justice and the need to reduce health inequalities (DoH, 1992, 1999). The introduction of day case surgery, rapid access clinics, and ambulatory care has reduced the length of hospital stay for chronically ill children and adults. At the same time, technological advances make the lives of these people paradoxically more, not less, medicalised, and create the need for the input of professional staff in the community. In particular, medical advances have improved the prognosis for children with CI to the extent that a group of children have emerged with long-term needs, some of whom remain dependent on technology for their survival and quality of life (Kirk, 2001). Accompanying these advances has been a move to care for children with CI in their own homes rather than in institutions in response to policies affecting all people with CI (DoH, 1989) and for sick children in particular (DoH 1991, 1996). However, Arnfield (2001) points out that while adults benefit from a district nursing service covering the whole of the UK, only 60% of the UK is served by a specialist community children's nursing team. The shortfall is filled by family members, most often mothers who are subject to financial and emotional stress as a result of this caring role (Twigg and Atkin, 1994).

As a result, almost 6 million women, men and children (DoH, 1999a) now take on a substantial caring role in their own home or community, forming the backbone of what is now known as 'community care'. Current macro policies focus on supporting families in the community but are firmly focused on preventative measures such as the Sure Start programme available to areas of deprivation and

poor health that aim to promote organizational partnerships to address inequalities in health. The situation for people who are already ill appears to remain unchanged under the Labour government, in which the majority of care is carried out by family and friends in ways largely unsupported by service providers (Twigg and Atkin, 1994).

Analysis of the literature shows that the primacy given to bio-physical well-being means that informal carers are increasingly expected to take on skills and procedures that are becoming more and more technological in nature (Atkinson, 1992), with little regard for the effects of this role on the carers (Arras and Dubler, 1994; Kirk and Glendinning, 1998). Several authors (Kirk, 1998, Swallow and Jacoby, 2001) have noted the skills and procedures which are increasingly undertaken by informal carers such as giving injections and complex medication regimes; it seems that, as medical responses to CI become more technological, so too does the role of informal care-giving. This is particularly true in the arena of caring for chronically ill children. Callery (1997) carried out a qualitative study of the experiences of parents whose children were hospitalised on a surgical ward. He suggested that conflicts arise from the contrasting nature of maternal and professional knowledge and located these knowledge bases within the 'private' domain of close contact and the 'public' domain of professional work respectively. However, as Kirk and Glendinning (1998) note, little is known of the mechanisms by which caring roles are adopted and supported clinically, of the experiences or perceptions of these roles and activities, or of the social and ethical implications of these roles.

An awareness of the physical, financial, social, and emotional effects of caring on the individual led to pressure from the National Carers Association (Parker, 1994) for Government and health and social services alike to recognise and address the problematic reality of care-giving. As a result of this, the Carers (Recognition and Services) Act (DoH, 1995) was introduced, giving carers the right not only to ask for an assessment of their own needs, but also the right to stop being a carer at any time of their choosing. Literature on the introduction of statutory requirements of the Carers Act (1995) points to the fact that its application in practice has been problematic on several levels. Research in this area (Ellis, 1993; Manthorpe and Twigg, 1997) is extremely critical of this needs-led assessment on the basis that carers find it difficult to ask for an assessment by clinical staff who had often formed their own value judgment of what the needs of the carers are. Awareness of these issues guided the decision to explore the experiences of family carers in this study. Current clinical responses to enduring needs are the subject of the following section.

Multiprofessional teamwork

The need to offer the emerging chronically ill population of children and adults a more responsive, ongoing service has demanded that multiprofessional team approaches to care became the cornerstone of contemporary rehabilitative and educational philosophies (Mackay et al, 1995, Lathlean and Le May, 2002). This is highlighted in policies such as the NHS and Community Care Act (1990) the Carers Recognition and Services Act (1995), and the NHS Plan (Department of Health, 2000). Each of these policies place responsibility on service providers to ensure

smooth and timely discharge of patients from hospital with appropriate multi-disciplinary community services in place to support the patient and family. In addition, the Education Acts (1981, 1989) and more recently, the Carers and Disabled Children Act (2000) place an imperative on local authorities to provide for multiple educational and rehabilitative needs in increasingly imaginative ways using a multi-agency approach.

Since the implementation of the NHS and Community Care Act in 1993, much academic attention has been paid to the working relationships between the various agencies involved in service provision. For example, Edward (1997) used qualitative interviews with multiprofessional staff working in a range of settings in the North-East of England, including a special school and a pre-school nursery, and found that staff often acted in a 'uni-professional' way, while thinking in a multi-professional manner. Hugman (1995) contrasts community health and social care for older people with child care in order to analyse multiprofessional boundaries in these major arenas of service provision and found that two of the emerging themes in health, social care and education are the need for staff to collaborate more effectively to achieve the best possible outcome for people with chronic illnesses, and the need to be more responsive to the 'consumers' of care. Greenwell (1995) asserts that each of these aspirations require people with illness to be partners within interprofessional teams. The difficulties associated with reaching such aspirations focus on the vertical hierarchies, professional cultures and power agendas, while the publication of *Working for Patients* (DoH, 1989b) and the remodelling of the NHS as an internal

market placed far greater emphasis on choice, information, standard setting, and patient satisfaction.

An explicit and implicit goal of multi-professional service provision for chronically ill people is conceptualised as 'rehabilitation' in health, social care and education of children and adults with chronic illness (Macduff, 1998). The continued emphasis on family approaches to care outlined above, promotes the notion of rehabilitative care for chronically ill people in order that they can live within their own homes, rather than in institutions. The predominant framework that underpins rehabilitation services is the International Classification of Impairment, Disability and Handicap (WHO 1980). The key concepts of disease, impairment, disability and handicap seems to suggest a linear causative structure that fails to emphasize the wide range of behavioural and environmental factors that may be important in shaping the incidence of and quality of life of people with CI. The adoption of such a reductionist approach has encouraged a diagnose-and-treat approach to rehabilitation that suggests an ultimate goal for patients, namely recovery and successful resolution of problems (Burton, 2001).

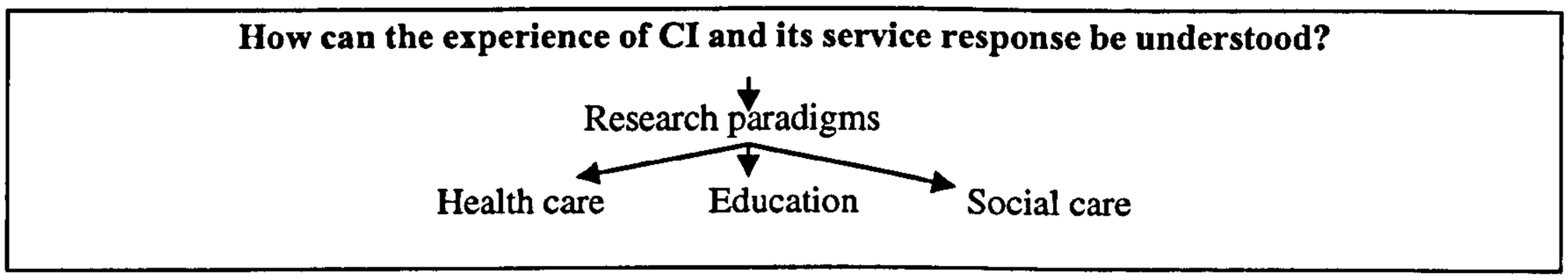
The literature in general emphasizes the need for psychosocial and behavioural goals but research on the processes and dynamics in which goals are formulated between staff and patients focus on the lack of understanding in this area (Roy and Andrews, 1991). Lawler et al (1999) identify the tension between establishing goals that encourage progress and recognizing the limitations placed on stroke patients by their ongoing chronic needs. They present rehabilitation as '*a sensitive area as a delicate balance needs to be struck in order to present a*

meaningful challenge and to promote recovery' (p.403). Using qualitative interviews and a grounded theory analysis of nursing records, they noted that nurses were reluctant to set honest, achievable goals for fear of upsetting and demotivating the patient. This led to a situation in which the majority of stroke patients at one year post-stroke were demoralised and depressed with the non-achievement of their ultimate goal which was total recovery. It was suggested from this that failure to set realistic goals about prognosis can be damaging to patients and to the patient/professional relationship.

While there is clearly a place for the medical model in which cure is achievable (Reed and Watson, 1994), the ideological and political approaches to care in situations in which a cure is not a realistic goal seem unable to look beyond the physical-medical parameters of the illness. There is clear evidence that collaborative rehabilitation between a range of health care professionals leads to definable benefits to chronically ill patients, particularly reductions in mortality and morbidity (Stroke Unit Trialists Collaboration, 1995). However, traditional approaches to stroke rehabilitation services have been underpinned by short-term frameworks which focus almost exclusively on physical rehabilitation. This contrasts with research into patients' experience of stroke which indicates that recovery is non-linear (Hafsteinsdottir and Grypdonck, 1997) and tends to be defined by involvement in the wider social world (Doolittle, 1992, Folden 1994, Nilsson et al, 1997) incorporating family roles and responsibilities, social membership, lifestyle and employment. In response to this, the Stroke Association (1998) called for the development of services that re-focus attention on quality of life and long-term care management that

addresses the burden of care on families. Despite this, a clear picture persists in the literature of the failure of stroke services to deliver a seamless service that equips patients and families to cope with chronicity (McLean et al, 1991, Stroke Association, 1994). Similarly, research indicates that parents and children with life-limiting illnesses such as cystic fibrosis are denied the opportunity to discuss death and dying but instead are offered 'rehabilitation' services and interventions that focus on the prevention of infection and maintenance of weight (Cappellie et al, 1989).

In summary, the contradictions and tensions inherent in providing heath, social care and education for people with enduring illnesses can be located within the medical hegemony and competition for resources demonstrated within Western models of service provision. Lack of political, ideological and professional understanding about the commonalities and differences in representations of chronic illness means that the research agenda has become increasingly diverse and imaginative in finding ways to explore the experiences of people with chronic illness, their carers, and the service responses to their needs. The various methodologies, areas of interest, and knowledge generated are the subject of the following section.



Experiential dimensions of chronic illness

Commonalities and differences in the experience of chronic illness

Early research on CI appeared to be firmly located within diagnostic-specific parameters that added to a body of specialist knowledge but had little meaning for practitioners working in general fields of health, education, and social care. More recently, there remains a tendency within some research and clinical care to treat CI in a manner that denies the commonality of processes involved in living with CI across the spectrum of medical diagnoses. Diagnostically driven studies of coping strategies among people with kidney failure (Gurkis & Menke, 1988), and psychosocial needs of children with epilepsy (Austin & Dunn, 2000) lead to descriptions of idiosyncratic consequences of the disease and theoretical understanding suitable only for the specific population of people suffering from one disease. It seems clear from studies of distinct chronic diseases that certain experiential features may be unique to each diagnostic group and cannot easily be compared to those with other diagnoses. For example, La Greca (1990) demonstrates the importance of peer acceptance and its effect on treatment adherence among adolescents with diabetes.

However, one problem with these diagnostic–specific studies is that they often de-select people with multiple pathologies from their sample group. For

example, Dennis et al (1998) deselected people with underlying malignancies and other illnesses in their quantitative study of the emotional wellbeing of stroke patients and their carers. Although statistics of prevalence of multiple pathologies are impossible to find, the fact that this de-selection is necessary suggests that having multiple diagnoses as part of the CI experience remains to be fully explored.

A second observation made of this type of research is that it lacks focus on the commonalities between experiences of chronic illnesses across and beyond diagnostic groups. The shared processes involved in adapting to life with CI have been placed in the practice arena by authors such as Christine Eiser (1993), a psychologist who became concerned that understanding of the shared ways in which people adapt to CI "*languishes in academic psychology journals, and is not even read by practising medical staff.*" (p.7). Eiser (1993) places enormous emphasis on a 'noncategorical' approach in which similarities hold across different chronic conditions. It seems that while chronic illnesses have diagnostic and prognostic differences, the processes involved in coping with these illnesses have many similarities in terms of psycho-social adaptation, understanding of which may influence service responses to chronic needs.

Initially, this type of homogenous research conceptualised CI largely within a discourse of individual tragedy, and findings were framed firmly within personal deficits. Theoretical models of coping in children, adolescents and adults all focus on behavioural, cognitive and/or emotional responses to both external and internal stressors or demands (Lazarus & Folkman, 1984; Eiser, 1993). For example, Carver et al (1989) studied adults with various diagnoses of CI and distinguished 13

different conceptual strategies ranging from problem focused coping such as planning and seeking social support, to behavioural and emotional coping strategies such as denial. These models have been criticized when applied to children's coping strategies on the basis that emotion based coping is far less obvious or easy for a child to demonstrate due to their language and cognitive expressional development (Compas et al, 1992). What is apparent from these psycho-social models is an assumption that chronic illness is always responded to by grief and mourning. Failure to adapt to CI is conceptualised within the language of maladjustment and psychopathology. This is challenged by French (1993) in her personal account of living with visual impairment. She states that,

"my denial of disability was not a psychopathological reaction, but a sensible and rational response to the peculiar situation I was in" (p. 70).

The problems inherent in adopting a maladjustment and tragedy approach to research into CI are exemplified within research on children with CI. Early studies carried out on individual diagnostic groups (for example, Spina Bifida and cystic fibrosis) drew conclusions that were extrapolated concerning the effects of CI in general on the individual development of the child intellectually and socially (Deasy-Spinetta et al, 1988; La Greca et al, 1990). This has been the subject on much interest with some authors concluding that CI can be devastating to maternal bonding and subsequent social development in the child (Bowlby, 1969; Bretherton & Waters, 1985). This, coupled with exploration of bullying and peer-group lack of acceptance due to disability (Hartup & Sancilio, 1984) led to the development of psychopathological models of care that conceptualised adjustment to CI in both

children and adults as an homogeneous process based on trauma and maladjustment. More recently, this 'personal tragedy' approach (Drake, 1999) has been challenged by studies that reveal the response to CI as one of resilience and survival demonstrated by normal growth and development, even in the face of serious and life-limiting diseases. For example, a quantitative investigation with Italian adolescents with cystic fibrosis and diabetes suggest that they are not at greater risk than healthy children of developing psychopathologies as previously thought; they cope well with life tasks and were able to make positive adjustments in their lives to their chronic illnesses (Cappelli et al, 1989). In addition, many writers have explored the ways in which children with CI experience friendships, concluding that peer relations and friendships are as important to the development of a child with CI as they are to a physically able child (Mulderij, 1997).

Biography and normalisation

Recognition of both the positive and negative complexity of coping with CI has resulted in increased awareness of shared experiences within representations of CI, expressed most commonly in terms of biography or life-stories. An emerging body of work attempts to combine homogeneity and heterogeneity through the exploration of biography and trajectory studies that identify common processes involved in living with chronic illness while at the same time acknowledging the importance of individual voices within the research process. A paradigm shift from the problematised, medicalised perspectives outlined earlier, towards more holistic 'life course studies' has been seen in the past 10 years, particularly in North America and

Great Britain. For example, Kralik et al (2000) compared the experiences of women who were given a diagnosis of various chronic diseases including diabetes, leukaemia and severe psoriasis. They drew conclusions about a common experience of being diagnosed in relation to the threat this posed to self-identity. In this type of research, assault on the physical self is conceptualised as biographical disruption (Bury, 1991), requiring biographical accommodation in maintaining control, adapting, and allowing the illness to become part of the biography of the person and the family (Corbin & Strauss, 1987). For example, Bailey (2001) explored the 'death stories' of 10 people suffering from Chronic Obstructive Pulmonary Disease (COPD) living in a Canadian mining community. Analysis suggests that patients and their families lived in constant fear of imminent death and they wished more than anything for nurses to understand this fear and to give their needs priority during an acute attack.

A common thread running through much biography work with both children and adults is analysis of the process of normalization. For example, Robinson (1993) explored the ways in which relationships evolve between people with CI and health care professionals using interviews with 40 British adults with various chronic conditions. She found a shift from 'problem-saturation' towards living a 'normal' life via a process of reframing which involved covering up difference by promoting independence, doing normal things such as maintaining a routine, and making trade-offs (for example, a woman requested a wheelchair in order to go shopping with her daughter, even though she could walk short distances). Similar processes have been uncovered in studies of childhood chronic illness, for example, Kanfl & Deatrick

(1986) identify four cognitive criteria for normalization in which families define life as normal through minimising the social consequences of their situation.

This approach is useful in that it encourages researchers and service providers alike to look beyond the functional impact of the illness, towards a temporal model located within the experience of the person and family. However, criticism of some types of 'insider', biographical research has rested on the fact that it samples participants who are able to talk coherently, and who are not in crisis. For example, Folden's (1994) grounded theory study of 29 stroke survivors relied on retrospective accounts of people who had made a good physical and cognitive recovery from the stroke. In particular, this retrospective approach has relied on accounts of the illness experience that does not capture the mundane, taken for granted aspects of the illness experience; or take into account a possible tendency to downplay the devastating effects of an acute crisis (Thorne & Paterson, 2000). Awareness of these issues guided sampling decisions in this thesis to ensure severely ill people with difficulties articulating their experiences were represented. This study employs longitudinal, observation methods in order to capture the every-day experiences of children and adults and their interfaces with staff and informal carers.

Disability framework

Two further substantive bodies of work appear to analyse the experience of chronically ill people as a homogeneous group; that is those using a disability critique as a framework, and those using the illness trajectory as a framework. The disability framework has become a highly politicised academic field for debate that

offers a critique of popular notions of disability that assume a tragic aberration that afflicts a minority of people. From the early 1980s a number of British disabled writers and activists (such as Mike Oliver, Paul Abberley, Paul Hunt and Vic Finkelstein) developed what became known as the 'social model of disability' in which disability is seen as the effect of social and physical environment that discriminates against and disables people with functional impairments. This critique drew attention to the fact that people with CI and resultant disabilities experience poverty, unemployment and discrimination as a direct result of societal and structural processes and environments that create and perpetuate disability. A further layer of complexity has been added to this debate by Shakespeare & Watson (1998). In their critique of research with disabled children, they argue for a balance between the individual experiences of disabled people and as homogeneous members of a disadvantaged group, and between understanding the commonalities and differences between the two approaches. This represents a subtle but fundamental change to the perspective offered by the Disability movement that has previously focused entirely on political and social aspects of disability without acknowledging the often disparate experiences of individual people with CI and disability. No-where is this more apparent than in considerations of issues of bodily impairment and physicality. Critics such as Crow (1996) and Williams (1999) point to the lack of analysis of the bodily experience of illness and disability and argue that it is important to explore all dimensions of the illness experience. This guided the decision to use observation as a data collection tool in this thesis in order to explore the daily realities of life with CI.

The Chronic Illness Trajectory

A generic approach to understanding CI lends itself to a framework pattern characterised by movement from diagnosis to death across the time continuum. American social scientists Corbin & Strauss (1988), Fagerhaugh & Strauss (1977) and Glaser & Strauss (1967) used grounded theory techniques to design a chronic illness trajectory though which people with any enduring illness move through stages at different times in their lives. The trajectory framework has evolved over 30 years of research and was developed from extensive studies on the dying process. It has since been refined by its authors using a range of settings and client groups and has been applied to a number of diagnostic groups including cardiac disease (Hawthorne, 1991), cancer (Dorsett 1992), multiple sclerosis (Miller, 1993), diabetes (Walker, 1992) and stroke (Burton, 2000). However, its application to the experiences of children with CI has received little attention for reasons that are unclear but may be located within tendencies to view children with CI as a homogenous group whose adaptation to CI is assumed to be located within cognitive and developmental stages rather than in individual biographies of living with CI (Eiser, 1993).

The trajectory describes eight mutually exclusive phases that move from prediagnosis, trajectory onset, crisis, acute, stable, unstable, downward and dying (Corbin & Strauss, 1992). The authors suggest that people can move in and out of a phase and return to a phase during a fluctuation in the illness courses. Burton (2000) carried out 14 qualitative interviews with a stroke patient and his wife to create a 'vignette' that explored the fit between the trajectory framework and patient experiences of stroke. He concluded that the long-term nature of the framework

reflected the fact that the physical, social, and emotional effects of stroke have an influence over family lives in the long-term and presents a challenge to service providers in relation to addressing the long-term needs of patients and their families.

In summary, it seems that academic understanding of the commonalities and differences between diagnostic groups is characterised by a growing understanding of the shared challenges faced by chronically ill people and their families; this has implications for service providers who come into contact with a vast array of diagnostic groups every day and who are expected to provide individualised, yet equitable care for these patients. Thorne & Patterson (2000) suggest that an understanding of both the generic experiences of chronic illnesses and its diagnostically specific complexities is vital in order to fully address the needs of people with chronic illness and their families. This study intends to carry out research with participants with a variety of chronic illnesses in order to explore the commonalities and differences between their experiences and the responses of formal carers to these commonalities and differences.

Listening to the voices of children with chronic illness

Despite increasing interest in the 'insider' view of living with CI, at the commencement of this study, the voice of children themselves was largely absent from research into CI and disability (Shakespeare & Watson, 1998, Baldwin & Carlisle, 1994). This is exemplified by the work of Hamre-Nietupski et al (1994) who carried out a large-scale quantitative study involving 312 American teachers

working in both mainstream and special education. Questions related to teacher perceptions of the possibility of friendships between students with disability and their able-bodied peers and the ways in which these might be facilitated. The perspectives of the children themselves remained to be explored in this study.

In contrast, the UN Convention on the Rights of the Child and the Children Act (1989) both acknowledge children's individual rights to be consulted on decisions, including those involving the court system, that affect them. Trakas & Sanches (1992) point out that children have been represented predominantly as passive in their illness trajectory. Their perceptions are generally understood as a stage of development (Biface & Walsh, 1980, Eiser, 1993) and the passive voice afforded to them has been placed within society's explicit desire to protect their welfare. However, a shift in thought within academia and professional circles now views children as active in the construction and determination of their own social lives (James & Prout, 1990). This new emphasis challenges the developmental approach of Piaget which views children as less competent adults, and instead shows children to be capable of making complex decisions.

Alderson (1993), in her account of *Children's consent to surgery,* revealed the ability of children to understand clinical information and make informed choices about their treatment. Cooper (1993) interviewed 24 boys from two special schools and found that pupils valued respite, relationships and opportunities provided within their schools. He argues for the moral imperative of research with children in enabling them to articulate their views as effectively as possible in order to shape services that are responsive to the wishes and experiences of children themselves.

More recently, Sartain et al (2000) explored the impact of hospitalisation on the biography of British children with CI and their families. Using a grounded theory approach, they interviewed children and presented the experience of hospitalisation in terms of disruption to routine, schooling, friendships, physical abilities, and having fun. Findings had implications for the effective shaping of services to meet the biographical needs of the children. The study represented a subtle paradigm shift in the value placed on the perspectives of children who were viewed not simply as a legitimate sample group but as 'competent interpreters of their world' (p.913). This guided methodological decisions taken in the present study that was designed to capture the experiences of CI from the child's viewpoint.

Listening to the voices of carers

Early research into the experience of care-giving was largely directed by feminist concerns about the taken-for-granted element of women's' work as caregivers within a nuclear family (Oakley, 1974; Croft, 1986; Finch, 1984). A second strand of research has documented the functional and economic aspects of caring on an individual level, using experiential, qualitative methods (Graham, 1991, Twigg & Atkin, 1994); and much more commonly at a quantitative macro level using statistical analyses of the costs and benefits conferred to the country by informal care (OPCS, 1990, Su et al, 1997). From this it has emerged that women (58%) remain more likely to be carers than men (42%) and that 9 out of 10 caregiving relationships take place within a family context (DoH, 1999). Langer (1993) criticizes this quantitative approach on the basis that it results in a static view of what is more

generally regarded as a fluid process. Twigg & Atkin (1994) assert that while such categorisation is important in structuring the experience of caring, there exists a common core to caring in which a shared set of experiences and problems can be explored. This study intends to follow the experiences of chronically ill people and their carers over a two year period in order to capture some of the temporal elements involved in their adaptation to CI.

At first glance, the literature on the experience of informal care-giving has little in common with that of care-recipients. Certainly, the substantive bodies appear discrete and independent at political, ideological and academic levels. Despite the apparent lack of common ground, closer analysis of the literature reveals that the trends identified in research into the experiences of people with CI share much common methodological and epistemological ground with research into the experience of informal caregiving. In particular, there has been a shift from quantitative, problematised studies that illustrate the 'burden' of care, towards a more complex understanding of the satisfactions of care and the shared processes between the care-giver and care-recipient. The emotional, financial, social and personal costs of providing informal care are well documented predominantly by researchers working in Britain, Scandinavia, North America and Australia. For example, in their positivist study of the impact of childhood atopic eczema on the family, Su et al (1997) interviewed Australian families and demonstrated the financial costs of caring for a chronically ill child in terms of the effects on employment, travel costs and numbers of sick days. They also identified costs concerned with time, sleep deprivation, and marital problems. These findings are mirrored by US studies (Aday

et al, 1989) and British studies (Callery & Smith, 1991, Callery, 1997, Glendinning, 1992). This body of work has an important part to play in alerting practitioners to the previously ignored needs of family carers.

A counterview to the dominance of burden began to emerge in the 1980s that highlighted the fact that caring could provide a source of identity and satisfaction for carers. The concept of mutuality, in which carers gain gratification and meaning in their situation, was developed by Hirschefeld (1981), and extended by others to include any positive quality such as common values, shared activities, and reciprocity (Archbold et al, 1992). Reciprocity has since emerged as a central concept that highlights the subtle and implicit 'give and take' that defines family relationships, within and beyond the confines of caregiving (Nolan & Grant, 1992; Finch & Mason, 1993). Although this work represents a movement towards understanding the complexity of family life with CI, Nolan (2001, p. 35) brings attention to the fact that, *"the intervening decade has seen disappointingly little work in this area"*. In one of the few studies to analyse the experiences of both the care-giver and the care-recipient, Cox & Dooley (1996) describe three basic interactive styles between carers and care-recipients ranging from positive and pro-active, through passive and accepting, to angry, negative and demanding (quoted in Nolan, 2001). Twigg and Atkin (1994) comment on the complexity of the relationship between the patient and the informal carer saying that,

> *"...caring takes place in a relationship ... The disability critique has rightly argued that caring cannot be examined separately from the needs and wishes of disabled people ... Focusing exclusively on the carer is, moreover, demeaning to the disabled person, who is made into an adjunct of somebody else-no longer the subject of their own life."* (p.9)

The apparent lack of exploration of the shared experiences within the care-giving/care-receipt relationship leaves unanswered questions about the ways in which health can be influenced and maintained within the family unit. This study addresses this gap by exploring the relationships between chronically ill people and their family carers.

Listening to the voices of professional staff

The quality of the relationship between families and professionals is said to be central to the experience of living with chronic illness (Thorne, 1993, Gibson, 1995), often characterised by professional scepticism, non-negotiation of roles and scarce information provision (Coyne, 1995). Swallow and Jacoby (2001, (p.757)) suggest that,

"The need for families and professionals to coexist successfully is recognized as critical to the successful management of chronic illness within increasingly complex health care settings."

However, understanding of the factors and care settings necessary to promote this successful coexistence remains unclear.

Attempts to understand the significance of relationships between people with CI, carers and health professionals have highlighted several factors that influence their development. These include the attitudes and values of professionals, the financial, emotional and social sources of stress for families, and the status ascribed to people with CI by policy makers. In response to the long-term management required for people with CI and their families, research is now emerging which is

focused on exploring the development of the relationship triad as families move through the trajectory (Clarke, 1999, Atkin & Ahmad, 2000). Several writers have attempted to represent relationships between families and service providers as a series of models. Rolland (1988) conceptualises the interface between formal carers, informal carers, and chronically ill people as a 'therapeutic quadrangle' in which the professional acts as an advocate and an adviser to the patient and carer rather than as a direct provider of care. Twigg & Atkins (1994) suggest that 'carers occupy an ambiguous position in relation to service provision' (p.11) and propose four models of the response of service providers to carers, namely carers as resources, as co-workers, co-clients, and as superseded carer. Nolan et al (1996) offer a fifth addition to this typology; they view carers as 'expert' in the care of the chronically ill person. This legitimises the carers' individual experiential knowledge built up over time, and the more general professional knowledge of service providers.

Despite these attempts to represent positive relationships and therapeutic interfaces, the emerging picture overwhelmingly points to misunderstandings and conflict between families and professional staff. For example, a recent study by Procter et al (2001) emphasises the 'obligate moral climate' in which assumptions are made by staff members about the duty to care for patients in family settings. They found that patients with complex needs were often discharged unsuccessfully when staff made inaccurate, often gendered assumptions about the ability and willingness of family members to take on a caring role. Similarly, studies of relationships between professionals and parents have largely focused on technology-dependent children (for example Kirk, 2001) and have revealed processes of role

negotiation and professional assumptions and expectations as well as the defining nature of long-term care of children with CI as contrasted with the demands and societal expectations of ordinary parenting. North American studies have revealed the often problematic relationships between parents of children with CI and service providers in relation to parental control, the development of trust and mutual judgements about competency (Diehl et al, 1991). Research has uncovered the expectation of staff that parents will be involved in the nursing care of their child (Brown & Ritchie, 1990, Callery & Smith, 1991) but that conflict arises when parents are expected to relinquish control to professionals during hospitalisation of the child (Swallow & Jacoby, 2001). There is evidence that such assumptions and expectations of parental involvement is defined solely by the professionals and is not discussed or negotiated with parents (Dearmun, 1992, Darbyshire, 1994). However, the ways in which the care-giver role alters when the child reaches adulthood have yet to be fully explored. Similarly, the passive voice ascribed to children means that within the context of care management and the negotiation of roles within the family unit, the agency of the child remains relatively unresearched.

The emerging picture is of a disparate body of research on the interface between people with CI, their carers and the professional staff who address their needs. This body of work has little shared dialogue in methodological or epistemological terms and results in a confusing picture that demonstrates the lack of understanding and knowledge in this area. This thesis will explore this interface from the viewpoint of all three participating groups, referred to hereafter as the therapeutic triad.

Conclusions

This review has interrogated the literature with regard to two main features; firstly, the ideological, political, historical, practical and experiential dimensions of chronic illness and secondly, ways of knowing about chronic illness. This analysis guided the focus and direction of this study in several ways concerned with a) the exploration of commonalities and differences in the experience of specific chronic illnesses, b) the importance of representing the temporal element of CI, and c) exploration of the interface between people with chronic illness and their formal and informal care-givers.

What emerges from this analysis is representation of dimensions of CI as a series of contradictions in relation to what defines the experience, the prevalence, and the political, ideological, and service responses to chronic illness. Conceptualisations of chronic illness are characterised by a dichotomy between the experiential, family based accounts of illness, and diagnostic, individualised studies that place the experience of illness in the context of specialised, curative frameworks. It is clear that both approaches have merit in influencing and guiding a professional and policy response to the experience of chronic illness. This research adds to this body of research by selecting participants with a variety of chronic needs and analysing the data in relation to commonalities and differences in representations of experiences.

Recently, interest in generic aspects of life with chronic illness has dramatically increased, generated largely by researchers working in Britain, Scandinavia, North America, and Australia. A considerable shift has been seen from

research carried out from an 'outsider' perspective to that of biography and trajectory work that places great importance on the voice of the person with chronic illness. This body of work highlights the importance of exploring the chronicity of needs across a life-span. Concerns about temporal aspects of CI guided the longitudinal development of this research in theoretical and methodological terms that are detailed later in this thesis.

The challenges and contradictions inherent in providing long-term care for people within enduring needs can be located within a political and ideological framework that promotes individual responsibility for health. The demands placed on services are met within a failing rhetoric of independent, inclusive living that continues to provide care in institutionalised, segregated organisations. The paradigm clash between the need for long-term support for enduring needs and the acute, curative model demonstrated in Western health care leads to a number of tensions and contradictions in the lives of chronically sick people and their families. Current agendas of health improvement and prevention, based on heavy investment in family based, primary care interventions, seem to have little resonance with the continuing health needs of chronically ill people and their families. These tensions are increasingly being explored by research carried out in Britain, North America, Scandinavia, and Australia, from the discrete, individual viewpoints of children and adults with CI, their family care-givers, and service providers. A growing body of work attempts to assimilate these diverse viewpoints within the context of the care-receipt/ care-giving relationship. This interface approach is reflective of experiential, practical aspects of CI and findings have the potential to guide political, and practical

responses to enduring needs. This study builds on this body of work by researching CI in a qualitative way that focuses on the shared processes at the interface between chronically ill people, carers and service providers.

Overall, the image of a 'healthier nation' (DoH, 1999) contrasts strongly with the national and international context of increased chronic illnesses over the course of a life span. Recognition of this fact adds credence to a view of society proposed by Marks (1999, p.18) as being made up of "*contingently able bodied*" people (thus implying the possibility of chronic illness and disability for us all). It is possible to suggest that only when society stops being theoretically absorbed by definitions of who is chronically ill, disabled and able-bodied, will society be able to create flexible policies and services that meet enduring needs experienced within a life span. Thorne et al (2000, p. 304) suggest that,

> *"... the current situation is characterised by insufficient knowledge and inadequate mechanisms by which to convince the majority of health professionals that care for chronic illness is an inherently different social enterprise than in care for acute or episodic illness"*

Although this was written after the commencement of this thesis, it encapsulates the intention of this study to explore this 'social enterprise' from the perspectives of those living and working in 'Our Healthier Nation' (DoH, 1999).

Chapter 3

Theoretical Framework

Introduction

A qualitative paradigm was adopted in this study, which was reflective of the aim to explore meanings, processes and perspectives of participants. Research methodology is debated with reference to trustworthiness, credibility and transferability and the use of a range of theories within the study is discussed in terms of the fit with method and data. A positivist approach, where-by a fixed theory must be tested, was rejected in favour of using an eclectic range of theories to fulfil specific roles. The purpose of the study is to generate knowledge about living with chronic illness rather than to test pre-determined theory as in a positivist paradigm. This is discussed in terms of criteria recommended by Sandelowski (1993). Humanistic theory is described in terms of its use as an organisational framework; symbolic interactionism and ethnography are discussed as interpretive tools, and grounded theory is outlined in terms of its use in data analysis and theory generation of the emergent theme of adaptation to uncertainty. The debate about the use of several methodologies in one study is rooted in a concern that this eclectic approach is more than 'a pick-and-mix pragmatism' (Darbyshire, 1994, p.46). This pluralism of methodologies is presented within a discussion of triangulation and demonstrates the ways in which understanding of methodologies such as ethnography altered and influenced the study over time.

The role of the researcher is explored both in terms of closeness to the data, and in relation to theoretical assumptions regarding prior knowledge and experience. The appropriateness of such concepts as reliability and validity in this qualitative study are questioned, and credibility, transferability, and dependability are adopted as

alternative criteria for judging the trustworthiness of the study. It is anticipated that the discursive discussion adopted in this chapter will allow the 'decision trail' (Koch, 1994) taken at different stages of the study to be transparent.

Trustworthiness

This study is essentially an exploration of processes and perceptions. This demands an interpretation of perceptions in a way that remains 'true' to the definitions and meaning that people give to the things that they tell me by ensuring that analysis remains 'grounded' in the data. The varied characteristics of participants in the study (not least, age, gender, ethnic background, social class, marital status) highlight the fact that interpretations of meanings might be influenced by a number of factors. In order to represent those meanings in a manner that is honest and credible, it was necessary to consider the criteria with which to evaluate the study. Kirk & Miller (1986) suggest that appropriate tests are reliability and validity: reliability is '*the extent to which a measurement procedure yields the same answer however and whenever it is carried out*'; validity is *'the extent to which it gives the correct answer'* (p.19). They suggest that these concepts apply equally well to qualitative research, a point illustrated by many research works looking qualitatively at health, social care, and education (for example, Baker et al, 1992). However, Robson (1993) questions whether these are in fact relevant to qualitative research and that their use may stem from the author's desire to appear 'scientific'. Awareness that these criteria may not be appropriate for use in this study led to analysis of literature on trustworthiness. Robson (1993) suggests that irrespective of approach, a central

concern of research is to establish its' 'trustworthiness'. In doing so, Shipman (1988) recommends that we should go beyond the traditional concerns of reliability and validity and move towards establishing **credibility, transferability,** and **dependability.** Achieving these requires a full description and interpretation of the research experience, a description of the context of the research so that a judgement of transferability or 'fit' can be made by readers (Morse, 2001), and a description of the ways in which interpretations have been arrived at via the inquiry (Koch, 1994; Guba & Lincoln, 1985). It is with these considerations in mind that the process of conducting this study is presented in this and other chapters and as much data as possible are given to substantiate aspects of decisions about methods and findings. Such a 'decision trail' (Koch, 1994) is described to allow readers to make their own judgements about the trustworthiness of this study.

Triangulation

A common method of contributing to the trustworthiness of data is the use of triangulation; the combination of multiple factors in the study of the same phenomenon (Cowman, 1993). This is based on the traditional assumption that the flaws of one approach can be overcome by using a combination of approaches (Denzin, 2003). More recent work challenges this interpretation of the importance of countering 'flaws' and instead emphasises recognition of those characteristics that are unique to each method that then have a unique influence on the nature of data that is collected. Breitmayer (1993) suggests that triangulation has two distinct aims: first that of **confirmation,** where the methods are designed to 'converge on a single,

discrete variable'. This is consistent with a quantitative, positivistic approach; and second, **completeness,** in which triangulation is used to examine the varied dimensions and complexity of an area of interest. Many qualitative works (for example, Lawler, 1991) use triangulation in the latter sense and this approach is consistent with the aims of the current study. **Theoretical** triangulation occurs when multiple theories and hypotheses are included in the same study for different purposes. In this study, humanistic theory, symbolic interactionism, and ethnography were used in terms of their applicability to methodology, data collection and data analysis. This is discussed in the following section.

Theoretical triangulation

At first glance, phenomenology, ethnography and symbolic interactionism all seemed to have philosophical underpinnings resonating with the principles and tenets of the research. Each of these approaches offers inductive, descriptive research methods which would allow me to capture the 'lived experiences' (Beck, 1992) of the people in the study. Drawing on a contention made by Morse (1989) that qualitative researchers tend to use methodologies eclectically without clear distinctions between them, Baker et al (1992) state that,

"To ensure rigour, ... qualitative data collection procedures should be explicit and consistent with the underlying assumptions of the specific approach selected" (p.1355).

This is no easy task considering that analysis of these methodologies revealed subtle differences in the beliefs and philosophies that underpin them, and that each philosophy has within it a long continuum of interpretations and schools of thought.

A further layer of complexity lies in the fact that theory can be used at different times and on different levels throughout the research experience. Sandelowski (1993) suggests that:

"Theory may enter (and leave, if it fails to earn its way) into a project at different points in time in the research process and it appears in different guises as the impetus and underlying rationale for the inquiry process itself, as an original project of a study, or as an extant formulation brought into a study for organisational or interpretive purposes." (p.217)

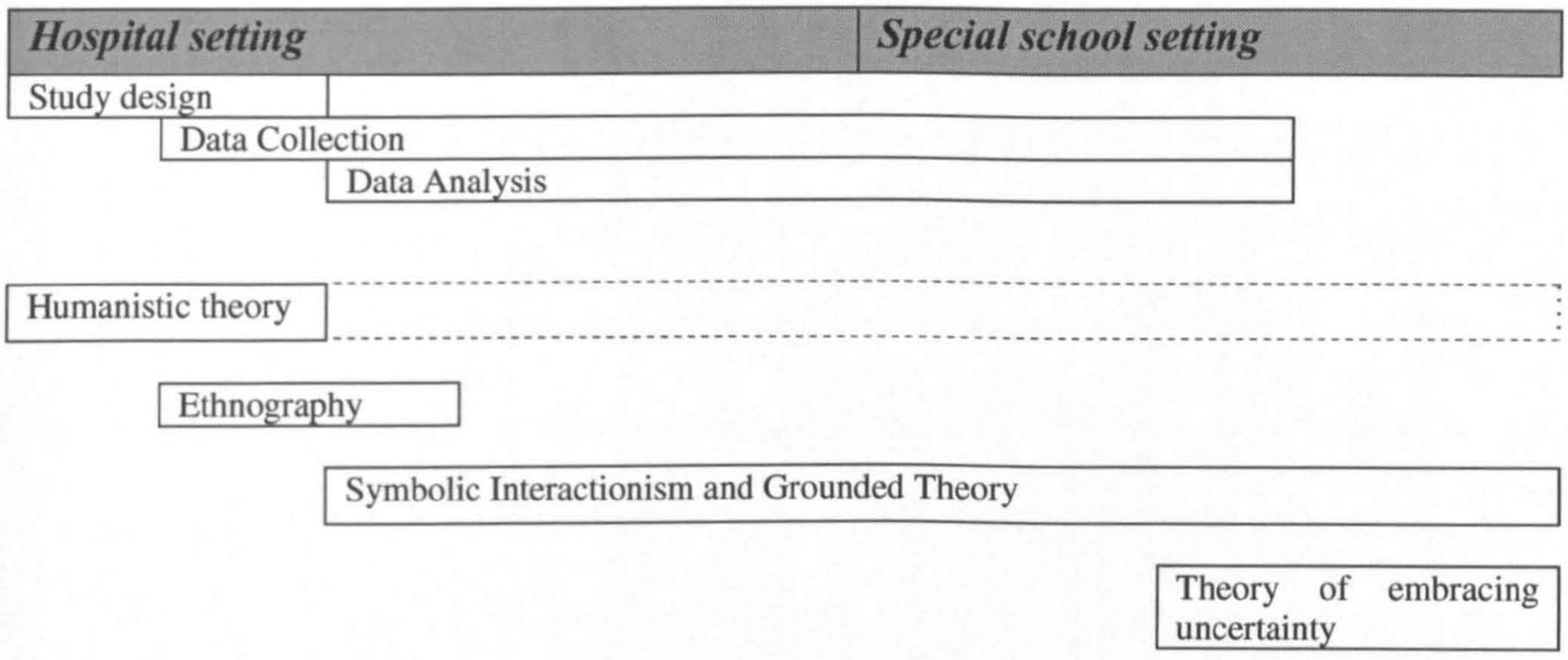
This theoretical triangulation has been the subject of debate for several years, fired most notably by Janice Morse (1991) who opposed such pragmatic use of theory as a 'sloppy mishmash' by 'self-taught' researchers such as Swanson-Kauffman (1986) who used a blend of phenomenological, grounded theory and ethnographic methodologies. In their influential paper, Baker et al (1992) argued against this method 'slurring' and contend that no methodology is credible if used inappropriately. Layder (1991) takes a more constructive approach and argues for an eclectic method that enhances both theoretical and practical relevance. More recently, Johnson et al (2001) reconceptualise method slurring as 'British pluralism' on the grounds that there are no 'pure' qualitative methodologies but that the application of ethnography, phenomenology and grounded theory occur on a continuum of interpretive, interactionist, social constructionist and hermeneutic perspectives. I share the belief of Long & Johnson (2000) that honesty, avoidance of deception and the provision of relevant evidence are just as achievable when pluralism of methodology is adopted as in single methodology. They contend that the principles of rigour and validity have as much appeal when methods and theories are used in combination.

In order to navigate these debates successfully, an understanding of the beliefs underpinning the philosophies was necessary in order to apply the methodologies rigorously and appropriately in this study. It seemed necessary at an early stage of the study to address my own, and other peoples, beliefs and assumptions on three levels within the chosen qualitative paradigm. To do this, Robson's (1993) three levels of assumptions was used as a framework, namely;

1. Reality (ontology),
2. Knowledge of that reality (epistemology) and
3. Particular ways of knowing about that reality (methodology).

In terms of ontology, it was clear that many of my own beliefs, as well as the research aims themselves, stem from the humanistic philosophies inherent in nurse training (Seedhouse, 1997). Symbolic interactionism and ethnography provided the appropriate interpretive and epistemological theory and grounded theory methodology was used to provide structure to the analysis process and the development of findings. The following sections describe the application of these theories into the research process, represented in figure 2.

***Figure 2*: Chronological use of theory**



Humanism

Humanistic theory has its roots in Ancient Greek philosophy and is based upon a respect for individual self-determination and free-will (Doyal & Gough, 1991, Seedhouse, 1986). Many of the professional groups concerned with health care, social care and education have adopted humanism on one level or another and concepts of health as independence, the exercise of autonomy, and self-determination are closely allied to humanistic philosophies of health (Procter, 2000). Many of the interpretations of humanism within the literature are woolly, contradictory and rely on the reader's own interpretation of vague terms such as existentialism. In an attempt to tease out meanings and ensure that humanism is applied in a rigorous manner to this study, the following gives a description of the ways in which humanism has been interpreted and utilised within this study.

- Naturalism: a belief in the reality of what can be perceived by the senses and found in nature (Jolley & Brykczynska, 1992). The focus of this study is on perceptions and the meanings that participants give to their own experiences.
- The unity of the body and soul: this emphasises the here and now, rather than the religious 'hereafter' (Jolley & Brykczynska, 1992). This is consistent with the aims of this study which is concerned with the 'lived experiences' of participants.
- Self-determination of the human being and the right to freedom of choice. This resonates with the disability rights movement, elements of which were drawn upon in the design of this study. It provides the rationale for providing each participant with an equal voice and an agency within the research process regardless of characteristics such as disability, age, cognitive ability or gender.
- The necessity of a moral system: within the tenets of humanism, this addresses freedom, autonomy, happiness and progress for all mankind (Doyal & Gough, 1991). This idea informed the application of data collection methods in a way which adhered to my professional code of conduct in terms of the use or abuse of the research relationship. This is discussed more fully in the chapter 4.
- The attainment of a 'good life' for each individual. Maslow (1970) and Rogers (1961) were the most popular exponents of this theory with Maslow's notion of self-actualisation having a profound influence of concepts of human potential and theories of therapeutic intervention for health and social care professional groups. This gives further credence to the call for tensions identified in the literature review to be resolved between provision for acute needs, set against provision for more enduring chronic needs.

Analysis of the theoretical stance offered by humanism gave an organisational framework on which to base research decisions in a structured, rigorous manner that was overtly consistent with my own beliefs and views about the world and about research participants. This process of analysis contributed to the 'critical eye' referred to by Bryman (1988) in allowing the research process to reveal organisational and other constraints that hinder or prevent a humanistic delivery of service. For example, Seedhouse (1997) points out that humanistic tenets such as autonomy and independence are difficult to apply within current health and education cultures. A commitment to these tenets led to the decision to give primacy to the voices of chronically ill people and their families, which in turn influenced sampling decisions taken at every stage of data collection. The rationale for the selection of the interpretive and organisational theories is now presented in the context of the organisation that humanistic theory conferred on the research process.

Ethnography

Ethnography was initially considered as a theoretical perspective that would provide a framework for interpreting emerging concepts and indicate directions the study would take in a way that was consistent with the aims of the study and with the humanistic tenets outlined above. In terms of a philosophical theory on which to base methodology decisions, ethnography offers three main tenets described by Laugharne (1995) as culture, naturalism, and holism. In particular, the emphasis on culture appeared to fit the aims of the study; by adopting observation methods (the main method used in ethnography), the culture of a group can be studied since,

"by discovering how a social group understands its world and the common meanings that the group shares, understanding of the group is more effectively achieved" (Laugharne, 1995, p.49).

In this thesis, the emphasis, identified in the aims of the study on p. 5, was on perceptions of experiences within the context of the culture created when different social groups, namely patients, formal carers and informal carers, come together as a result of illness or disability. Ethnography is fundamentally concerned with developing knowledge about how societies create social order (Porter, 1998). In order to achieve this it has developed observation as a primary data collection tool (most notably used by Hammersley, 1986). According to Garfinkel (1984) data is interpreted through the observed experiences and interpretation of those experiences provided by participants. Social order is analysed through participants' perceptions and experiences of that order.

With this in mind, semi-participant observation was carried out on two wards in a general hospital. Data analysis revealed a variety of organisational and contextual information about daily routines and staff roles and responsibilities. This contextual information was quickly augmented by findings that showed patients proactively seeking out other patients with similar diagnoses in order to make comparisons of progress and goals. Preliminary data analysis indicated that these interactions and interpretations of meanings about those interactions influenced the experience of uncertainty within the illness trajectory. Thus, the interactions between people and the processes by which adaptation to uncertainty in chronic illness were negotiated became the primary focus of the study. The principles of ethnography gave little guidance on how to manage the interaction between macro/contextual

issues which shape organisation structure, purpose and outcomes, and micro/process issues which focus on interaction within a defined setting (Atkinson & Hammersley, 1994). It became clear that the relationship between culture and context that arose when participants came together as a result of illness within the hospital setting was far more complex than ethnographic principles would suggest. In particular, observation as a method and ethnography as a methodology gave little clue about exploration of the possible interaction between the acute curative model of care in the hospital setting, and the need for patients to seek out similar patients for whom a cure was an unachievable goal. This inhibited the introduction of theoretical debates about the structure and function of the hospital setting which were not necessarily perceived by those whom data are collected (Porter, 1998). This perspective imposed limitations on the research as it prevented an analysis of the setting under investigation in relation to the structural cultural assumptions implicit in Western models of health care. The need to consider wider theoretical debates contrasted with the ethnographic commitment to capturing a picture of 'reality' through an analysis of patterns and events, perceptions and interpretations as depicted within the research setting.

Symbolic interactionism offered a way out of this theoretical mire since it views human beings as able to define their interactions and shape their actions. In contrast to ethnography which focuses on the immutability of social order as perceived by those creating that order, symbolic interactionism recognises the role of human agency in producing change (Porter, 1998). It therefore has a dynamic component that can be lacking in ethnographic studies. This emphasis on humans as

active creators in their world resonated much more closely with the complexity of the debates identified in the literature chapter and mirrored the initial findings from observational data which highlighted the impact of biography and agency of the participants in shaping their world. This approach therefore became the main interpretive theory that guided all subsequent decisions concerning data collection and analysis.

Symbolic interactionism

Symbolic interactionism represents a major tradition in social science philosophy. Originating from the work of Mead (1934) and later of Blumer (1969), symbolic interactionism rests on three premises: Firstly, people act towards their physical environment on the basis of the meanings that they hold about the things and beings in that environment. Secondly, these meanings arise from the social interactions between people; these interactions are symbolic because communication creates or produces language and other symbols. Finally, these meanings are created and adjusted through the interpretive process:

"*The actor selects, checks, suspends, regroups, and transforms the meanings in light of the situation in which he is placed and the direction of his action ... meanings are used and revised as instruments for the guidance and formation of action.*" (Blumer, 1969, p. 5).

The Blumer-Mead version of symbolic interactionism regards people as competent interpreters of their world and therefore appears to contrast with the ethnographic tradition of gaining a snap-shot of cultures that appear static and unaltered by the research process. This 'pretension' of ethnographic realism is

challenged by Denzin (1992) in his post-modern interpretation of symbolic interactionism. While symbolic interactionism mirrors a concern of ethnography for "*close and reasonably full familiarity with areas of life under study*" (Blumer, 1969, p.37), Denzin calls for a shift from attempts to obscure, decontextualise, and overtheorise the presentation of the lived experience of participants. Instead, he suggests a move towards a critical appraisal of "*how interacting individuals connect their lived experiences to the cultural representations of those experiences.*" (Denzin, 1992, p. 74). Although Denzin particularly emphasises cultural and feminist studies that expose 'racial, class, ethnic and gender biases' (p.151), this stance offered a way of incorporating a growing awareness during the study of the apparent denial of chronicity in the care of people with disability and chronic illness. As identified in the literature review, this can be located in a disability critique of acute, medicalised service provision that refuses to acknowledge 'failure' to find a 'cure' for the chronically ill person. While this disability critique formed only one of many perspectives that informed the research process, it influenced my increasing dissonance with the principles of ethnography. I share Denzin's belief that interpretive interactionism must explicitly engage in cultural criticism. This emphasis on critical exploration resonates with my position as a practitioner/ researcher, but created a methodological tension in this research between the adoption of a naturalistic perspective in which the research acts as a vehicle for exploring the lived experiences of participants and an interpretive perspective which locates these experiences within the wider debates explored in the literature chapter. Creating a balance between individual, naturalistic concerns and theoretical, macro

understanding was a task that demanded an exploration of the role of the researcher in making sense of the data. This is the subject of the following section.

The Role of the Researcher

Implicit within the use of qualitative theory and methodology is the assumption that the researcher will develop *'intuitive understanding'* by *'immersing ourselves in others' lives'* in order to share *'full recall of data'* (Richards, 1998, p. 319). The researcher will then be required to acquire the ability to abstract or to escape the data in order to generate theory. The task of distancing one's self in order to provide a theoretical level of understanding sits uncomfortably with the requirement of immersing oneself in the data. This created a tension experienced during this project, not least because the literature provides little debate about the conflicting needs both of closeness and abstraction while maintaining the meaning and vitality of the data. Richards (1998) comments that *'the challenge of getting distance is far more critical to good analysis and far more difficult than getting close'* (p.321).

Current debates concerning closeness to data are sometimes couched in the context of an assumption that the researcher is simply a conduit from which data will emerge, thereby denying the opportunity for acknowledgment about the influence of one's own life experience and professional judgement (Miles & Huberman, 1994, are a notable exception). Some qualitative authors, notably Baker et al (1992), address this tension in terms of the differences between phenomenology and grounded theory. They contend that an inherent difference between these theoretical stances lies in the requirement to put prior experience to one side. Grounded theorists seem

to waver on their position here, some claiming that no effort is needed to put aside assumptions – in fact, previous experiences are data (for example Baker et al, 1992). Other grounded theorists contend that as long as the researcher explores their own beliefs and assumptions in terms of the data, then that is all that is required to establish data collection and analysis procedures (Strauss & Corbin, 1994).

It seems each methodology suggests that awareness of the tension between distancing and immersion is necessary in order to establish rigour and trustworthiness (Koch, 1995). Regardless of the emphasis given to the relative merits of distancing and immersing oneself in the data, phenomenology appears to be interested more in the influence the data has on the researcher, while grounded theory suggests a more objective approach in that the researcher works on the data and can set aside presuppositions at will. In her discussion of ontological reality, Koch (1999) suggests that the way forward in this debate is to become self-aware of one's own preconceptions and beliefs and to accept that you take this awareness with you into the interpretive journey. Koch (1999, p. 28) suggests that,

> *"You would take this self-awareness, this sense of reality as a human being in the world, with you into the interpretive act. When you ask your participants to tell their story, you would accept that this story is their construction of reality."*

She draws on the work of Guba & Lincoln (1985) who favour a constructivist interpretation of the need to balance distancing with immersion by suggesting that presentation of findings is the result of competition between competing socially constructed realities, of which there are many within any interaction or situation.

As an experienced nurse, I had preconceptions and judgements at every stage of the research process. Phenomenology initially guided the theoretical framework on the basis that I would gain access to the 'life-world' of participants and would be able to 'bracket' my experiences and assumptions (Oiler, 1982). While I found I was able to acknowledge and explore some assumptions via a process of peer-review and regular meetings with project supervisors, the task of 'bracketing' experiences proved impossible. As a practitioner, I had ideas and perspectives that informed the processes of sampling and data collection. My tacit, experiential knowledge was valuable in terms of communicating with staff and patients, and in terms of knowledge of the organisations, all of which contributed to the emerging focus on process elements of living with chronic illness. Rather than 'bracketing' my experience, it became more important to think critically about the ways in which my knowledge informed and influenced the study. Resolving this tension required me to adopt the interpretive approach advocated by Denzin (1992) and actively engage in an analytic process which moved iteratively from data to theory and theory to data via my experiences and interpretation of the research process. This process was entirely consistent with symbolic interactionism, on which grounded theory is based. Consequently, grounded theory was considered as an approach to data analysis.

Grounded theory

For the purposes of this study, grounded theory offered a way to study human behaviour and interaction over time, providing a highly structured approach to the development of explanatory theory about stages and processes (Morse, 1992).

Grounded theory has become well established in health care and educational research, partly because its detailed process elements are easily accessible to those who are unfamiliar to carrying out their own research and partly because these very elements lend themselves to an audit type trail for those interested in making qualitative research into a scientific rigorous paradigm in its own right (Glaser & Strauss, 1967, Glaser, 1992).

The key aspects of grounded theory are the use of theoretical sampling and constant comparison. In theoretical sampling, the initial data collection and analysis guide future sampling decisions – in this way, the phenomenon guides the sampling strategy. In this study, the discovery of key concepts such as co-ordination of care and reflexivity guided the decision to extend the project to examine the experiences of children who had contrasting diagnoses and experiences of chronic illness over the time continuum (for example cerebral palsy and cystic fibrosis), rather than to choose children with head injuries as was the initial proposal. Theoretical sampling has been criticised (Becker, 1993) on the basis that it can lead to purely descriptive narratives lacking theoretical conceptualisation that might lead to improvements in service development. Chapter 6 reports how this study did in fact move through a descriptive level of analysis (Close & Procter, 1999) to a level of increasing theory generation.

The constant comparative method lies at the heart of grounded theory and is the principle method by which codes, categories, and finally theories are generated by a process of identifying new properties via comparison until 'saturation' is reached whereby the data no longer reveals new categories (Glaser & Strauss, 1967; Strauss & Corbin, 1990). This rigorous process gave structure to the process of data

analysis in this study, discussed more fully in chapter 6. Within this process, data were broken down and labels were given by asking questions such as 'What is happening here?' Each label or 'code' was compared so that their dimensions could be explored and similar phenomena became grouped together into 'categories'. The process of categorizing represents a move towards conceptualising the data in an abstract, analytical manner that involves becoming aware of properties and dimensions and the relationship between each code (Strauss & Corbin, 1990). In the tradition of symbolic interactionism, categories incorporate the dimensions of both patterns of behaviour and of socio-psychological processes within the data (Strauss & Corbin, 1994). This had the effect that the emerging theory was both descriptive of the experiences of participants and was explanatory in terms of illuminating the social processes involved in the area under study. Categories were then compared with each other in order to explore how their dimensions contributed to an overall theory. Saturation was reached when no further properties or dimensions were revealed and a pattern of relationships between the categories had been identified, interpreted and abstracted and these abstractions tested out in the context of a constant comparison with the data. This process allows the theory to be traced back to the original data, thus contributing to the trustworthiness of the study.

Conclusions

The literature on chronic illness lends considerable support to a focus on lived experiences, social processes and meanings that participants hold about their lives. In this study, exploration of the interface between clients, formal, and informal carers

sought to understand the meanings and processes held by participants. This is consistent with the adoption of a qualitative, inductive paradigm in this study.

In order to select approaches and methods sympathetic with the aims of the study, it was necessary to explore both personally and professionally held beliefs within the context of a debate concerning the insider/outsider role within the research experience. A central concern in a rigorous, trustworthy research study is the adoption of appropriate theories, methodologies and methods, with a clear rationale for the selection of those, as well the rejection of the many other tools on offer within the qualitative paradigm. Sandelowski's (1989) advice on the use of theory adds to the debate about trustworthiness by calling for researchers to be clear and honest about their use of theory. In this study, humanism was used as an organisational framework which reflected and made transparent many of my own personal and professional beliefs, and the ways in which it informed decisions about structure, methodology and method. Symbolic interactionism and ethnography informed the selection and use of methods of data collection and grounded theory conferred structure to the process of data collection and analysis.

In order to ensure the rigour called for by Sandelowski (1993), it became necessary to overcome the difficulty alluded to by Swanson-Kauffman (1986) in describing the web-like, cyclical research process in a linear format. During this process, the tenets of phenomenology and ethnography were found to be incompatible with the emerging direction of the study towards interactions and shared processes. It would have been easy simply to 'edit out' the influence of these theories early on in the study. However, to do so would have denied the philosophic

complexity of embarking on a research project such as this. It would have also denied the process elements involved in applying and exploring these theories to their full potential. In presenting the chapter in this manner, it is anticipated that the reader can follow the 'decision trail' (Koch, 1994) taken within this study in terms of theory, methodology and method. This challenges the commonly held view that a theory and method can be selected and applied unproblematically and unaltered during the study. My experiences and understandings of phenomenology, ethnography and symbolic interactionism altered over time as the fundamental differences between them became apparent. The effects of these growing appreciations are evidenced in the following chapters on sampling and data collection.

Chapter 4

Selecting and accessing a sample

Introduction

The use of purposive and theoretical sampling is discussed in this chapter in relation to the ways in which sampling decisions were taken in order to drive theory about the realities of living with chronic illness. Samples were taken from groups of participants with differing cognitive and physical abilities, vulnerability and perceived power within the organisations in which they live and work. The inherent tensions experienced during the process of sample selection are debated within the context of conferring rigour, trustworthiness, and ongoing, reflexive ethical integrity in terms of the influence they had on both theoretical and pragmatic decisions about sampling.

Both purposive and theoretical sampling criteria at each phase of the study are identified, drawing from a combination of analysis of the literature and detailed knowledge of the settings and client groups held by the research team. The first section describes and analyses the sampling criteria developed for each phase of the study. Later sections describe the more pragmatic process of identifying and accessing the actual sample group in relation to maintaining ongoing informed consent. Ethical integrity in relation to sampling decision-making is then considered and a discussion is made of the termination of the researcher /participant relationship.

Purposive and theoretical sampling

Concern over sampling decisions is traditionally associated with quantitative research and manifests itself in a preoccupation with representativeness and generalisability of findings. However, in qualitative work, sampling is driven by

theory in order to illuminate the issues under study and '*to uncover multiple realities*' (Kuzel, 1992). Because this study intended to explore the multiple realities of patients, carers and staff, quantitative techniques such as stratified sampling and cluster sampling were rejected in favour of theoretical sampling whereby the experiences of participants influenced and guided data collection at each stage of the project (Glaser & Strauss, 1967). Within this context, sampling can be defined as the means by which a selection is made from the basic unit of any study (Burgess, 1984). In this study, in order to explore the interface between patients, carers and staff (triad) longitudinally, it was necessary to consider a variety of sampling units, namely, patient, child and carer interviews, observed incidents over time, and staff questionnaires.

Within the tradition of grounded theory, initial sampling was purposive in that sampling decisions were driven by a need to access those participants most likely to have experience of the area of interest (Robson, 1993) and in terms of their usefulness to the research aims and subsequent development of theory (Reed & Procter, 1995). Analysis of data that resulted from this sampling technique then led to the sample being extended in ways guided by the emerging theory. This is referred to as theoretical sampling, described within the context of grounded theory by Glaser & Strauss (1967) as:

'the process of data collection for generating theory whereby the analyst jointly collects, codes and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges' (Glaser & Strauss, 1967, p.45).

At the start of this study, it was necessary to define the criteria for initial sampling decisions using issues highlighted in the literature review to explore the

aims of the study outlined in chapter one. In order to address the management of chronicity at the interface between chronically ill patients, informal carers and staff, it was necessary to select a hospital that would provide access to this triad. This purposive selection process was guided by the principles of sampling identified by Field & Morse (1996), namely, appropriateness and adequacy. These principles dictate that the researcher chooses participants and situations likely to give information and knowledge appropriate to the needs of the study and require an explicit identification of the initial sampling characteristics.

In this study, decisions were driven by a desire to develop theory that was grounded in the data rather than simply selecting groups or sampling units likely to confirm a theory based on the researcher's prior knowledge or experience. Reed et al (1996) point out that this commitment to grounded discovery can lead to reluctance to define sampling criteria, which can ultimately lead to an over-reliance on convenience and serendipity, rather than on rigorous decision-making. Similarly, it became apparent that the demands of theoretical sampling criteria were often at odds with practical and ethical concerns within the field. In particular, accessing a sample of people required ongoing permission to be granted by a number of people at different stages of the project, particularly since the research revealed new avenues for sampling at each stage. This inherent tension between wishing participants to consent for the purpose of theory development, while simultaneously protecting the rights of vulnerable individuals, became a principal concern in the application of sampling within this study. The pragmatic process of applying theoretical criteria were therefore influenced by the need to:

- Maintain methodological and theoretical rigour and trustworthiness
- Explore ethical considerations, in particular conferring ongoing, informed consent
- Ensure that sampling decisions were driven by emerging theory in a way that allowed for testing of that theory rather than purely seeking confirmation of a theory
- Acknowledge and minimise researcher bias in sampling decision making
- Acknowledge the ongoing balance between pragmatic and theoretical considerations in sampling

Concern over these themes influenced and guided sampling decisions at each stage of the study. The sampling characteristics for each phase are described in the following section, followed by a discussion of the identification and accessing of the actual sample group.

Hospital setting

Organisational context

The literature review in Chapter 2 reveals a number of themes that were expected to be pertinent within the chosen organisation, in the context of studying the management of chronicity at the interface between patients, carers and staff. These themes included the expectation of multi-professional working via the adoption of joint care planning and shared record keeping, and the development of a specialist multiprofessional stroke unit for which patients are selected from general medical wards and take part in a intensive rehabilitation with a variety of therapists. The purposive sampling criteria for the selection of this research site was:

1. High incidence of chronic illness among local population.
2. Range of services to cater for the multiple health needs of patients from diagnosis onwards.
3. Evidence of the development of multidisciplinary working.

A large General Hospital in the North of England was selected as the base for selection of the sample groups of patients, carers and staff, which met the above criteria. The explicit interest described by staff within the hospital in developing multiprofessional working provided a theoretical mirror to placing my findings within the wider context of national policies on multiprofessional working and therefore provided an opportunity for a fertile area for research. At a more pragmatic level, it was also anticipated that staff working within an organisation claiming overt interest in multiprofessional working might be willing to facilitate this project.

Geographically, the hospital serves a large urban area (population 83,704) in the North East of England. Residents of this area have a higher than average incidence of health problems, reflecting the wide extent of low incomes and unemployment in the area (South of Tyne Health Commission annual report (1994/95)). In this area, the hospital chosen as the research site had the highest bed occupancy rate in the Northern Region for stroke patients in 1993-94. At the commencement of the study in 1993, cerebrovascular disease (causing a stroke) was the main cause of death in 10.35% of female and 8.32% of male deaths in the area. This was significantly higher than the national average and the area's Health Commission began regular health promotion schemes (1993) to promote stroke

awareness and knowledge about the effects of smoking, poor diet, and lack of exercise. In this way, it hoped to achieve a reduction in the incidence of stroke and long-term disability by 2000.

Within this organisational context, choosing stroke patients with multiple needs and multiple therapists gave access to the interface between the triad under study, namely, patients, carers, and staff.

Stroke patients

In the hospital setting of the study, it was necessary to define stroke in order to accurately identify and access participants who had suffered a stroke. Cerebrovascular accidents are caused by either bleeding into the brain or blockage of the blood supply to the brain. People who have a stroke usually suffer chronic symptoms, the type and severity of which depend on the extent of damage to the particular area of the brain. Symptoms include facial weakness, loss of swallowing ability, lack of muscle coordination, impairment of speech, impairment of bladder and bowel function (Rudd et al, 2001). Patients who were given a diagnosis of TIA (transient ischaemic attack, sometimes a precursor to a full stroke, Lovett et al, 2003) were excluded from the study on the grounds most would suffer no chronic health needs and therefore would not illuminate the longitudinal interface between patients, carers and staff that was the focus of this study.

Despite the existence of several ethnic groups within the catchment area of the hospital, all patients (and their families) admitted with a stroke during the study were of white English origin. Consideration was given to extending the time limit

spent in the field to allow for selection of patients from ethnic minorities. However, figures taken from hospital admission records showed that people from ethnic minorities were rarely admitted, bearing out literature (Greiner et al, 2003) that shows that people within ethnic minority communities choose home care rather than hospital care. Capturing this issue would have entailed redesigning the project to incorporate exploration of home care for people with strokes, when the focus of this study was about the longitudinal interface between patients, carers and staff within organisations.

Following a stroke, a patient may be admitted to hospital, although the person's GP may make the decision to keep them in their own home for reasons that remain unclear but may be to do with perceived family support, the patients age, and the severity of the stroke. For the purpose of sampling, there was no way of predicting how many stroke patients would be admitted in any one period of time. Studies such as the Oxford Community Stroke Project (Bamford et al, 1990), that attempted to project the number of patients with first ever strokes, show the number of patients admitted with stroke vary dramatically from one month to the next and from one year to the next. Once ethical approval was granted, several recruiting options were considered, including the idea of an 'on-call' system in which staff would telephone me whenever they admitted a stroke patient. It was felt, however, that this would place unnecessary demands on staff and might potentially cause stress to patients at an already stressful time. The option of visiting two wards from within the medical unit daily to identify and recruit any stroke patients was adopted in order to gain a picture of the interface between patients and staff from initial

contact. A daily trawl over a period of two months through that day's admission records on each ward revealed a daily average of one patient admitted to each ward who were identified as potential participants. Permission to approach these patients was sought from the nursing staff. However, once a patient was admitted and identified as a potential candidate, I was asked by staff to wait on average four days before the patient was given a definite diagnosis. The issue of waiting for diagnosis became one of the main focal points of the study, since it influenced the trust between patients and staff, stress levels among carers, and defined the period as one of frustration and uncertainty which influenced subsequent acceptance of the certainty of chronicity for many months following discharge from hospital. This was frustrating but attempts to persuade staff to allow me access to patients pre-diagnosis proved fruitless. It is possible to suggest that staff were threatened by the research process and by the fact that they knew I was a practicing nurse. In addition, it is interesting to consider the reasons for feeling the need to 'protect' patients at what staff perceived to be a very stressful time for patients and their families. This issue is considered in more depth in the concluding chapter of this thesis.

Patients were initially asked for their permission to meet me by a staff member rather than myself and were given an information sheet about the study (see Appendix 1.1). Even though this process relied on staff members' accurate interpretation and representation of the research study to each patient, it was anticipated that patient would find it easier to make an informed decision if approached in this way. In fact, five patients did decline to take part, saying they felt the process might add to an already stressful time. These patients were of varying age

and gender, all with close family members in attendance; the reasons for refusal, and the attendant effect on study design and theory development are difficult to tease out without further information about these patients. This process highlighted the tension between protecting the rights of these vulnerable patients and wanting all stroke patients to take part for the purpose of theory development.

The first contact between the patient and the researcher was made in person during which patients were asked to sign a consent form (see Appendix 1.1). A schedule of observation periods was agreed upon, or if patients agreed only to be interviewed, a suitable time and place for the interviews was arranged.

	Interviews only	Observation only	Both methods
Male	1	2	3
Female	2	1	3
Total	3	3	6

Table 2: Method distribution chosen by patients in Hospital setting (n=12).

Table 2 indicates that out of a total of 12 patients who participated in the study, 1 patient declined to be interviewed but agreed to observation, 2 patients were unable to be interviewed due to speech difficulties. Similarly, 3 patients declined to be observed but agreed to be interviewed. (See appendix 10 for further details of participant groups)

Informal carers

The literature attempts to categorise and define informal caregiving in several different ways (Nolan et al, 1996, Low et al, 1999), each of which had potential

currency for the purpose of the study. However, it was important to allow the data to lead the way and as such, patients identified who they felt was their main informal caregiver in terms of practical, physical, emotional and / or financial assistance. This might have been a neighbour, a friend or a voluntary worker but in practice was always either a spouse (n=6) or a daughter (n=4) of the patient. Of the 10 informal carers who participated in the hospital phase, only 2 were male, a fact that may or may not reflect the predominantly working-class catchment area in which gender roles were clearly demarcated with women carrying out the majority of caring work.

The literature on caregiving indicates that previous caring experience has an influence on interactions with professional staff (Cohen et al, 1994), on the patient's experience of chronic illness (Nolan et al, 1996), and on the carer's own health needs (Low et al (1999). Purposive sampling criteria therefore demanded that carers should have a range of caring experience. In fact, several carers (n=6) identified by the stroke patients did have other caring responsibilities aside from looking after the stroke patient, making it unnecessary to extend the study to include or exclude any carers identified by the patients. Similarly, the carers identified by patients demonstrated a range in age (from 30 – 82 years).

Contact with the informal carer sample relied on permission from patients and was made initially by an informal meeting on the ward. Identified carers were given an explanatory letter and consent form (shown in appendix 1.2). This was then followed up with a telephone call to ensure that the person felt happy to be interviewed. Participants were given a choice of venue for the interviews; either on the ward or in their own homes. Three participants chose their homes, 7 chose the

ward for the first interview; at the second interview all participants invited me to their homes. The interviews were followed up with a letter thanking them for their participation and a copy of the interview transcript.

Professional groups

Previous studies that use similar methods to those described within this thesis rely on participants to provide names of all the professionals supporting them (for example, Kirk 2001). This relies on full participation of those staff and can lead to very small sample numbers. In this study, the questionnaire of professionals was an attempt to address the generalisability of issues arising from the analysis of client data and to seek confirmation or disconfirmation of the themes identified in previous data. Analysis of the interview and observation data indicated that staff involved in the care of participants came from a variety of professional organisations. The most effective way to reach professionals from such disparate groups appeared to be via a questionnaire aimed at a range of professional groups and organisations involved in the care of stroke patients. It was anticipated that this breadth of representation would contribute to an understanding of working with stroke patients and their carers.

Interviews with patients and carers were held concurrently with the distribution and analysis of questionnaires. A pilot questionnaire was initially carried out which was analysed on a structural level in order to ensure it was acceptable to clinical staff in terms of content and length of time spent to complete. Table 2 shows the occupational distribution of both pilot and hospital phase respondents. It is

important to note that the pilot data was also used at a content level in data analysis, rather than being disregarded as in quantitative research. For example, Yin(1994) regards pilot studies as a '*laboratory*' (p.74) in which variables and approaches can be manipulated and tested. I prefer to share Robson's (1992) interpretation of pilot studies which is to view them as meaningful case-studies in their own right that provide insights into the area under study.

Professional group	**Number of pilot respondents**	**Number of Hospital setting respondents**
Doctors	3	5
Staff Nurses	2	5
Social Workers	3	2
Physiotherapists	1	6
Speech and Language Therapists		10
Occupational Therapists		3
Total	9	**31 (50% response rate)**

Table 3: Occupational distribution of questionnaire respondents from 10 NHS Trusts in the Northern Region

Structural alterations were made following analysis of the pilot questionnaires, and the subsequent questionnaire was completed by 31 professional staff working within 10 NHS Trusts in the Northern Region as shown in table 3. The sample group were identified via gatekeepers within each organisation who were relied upon to provide names of staff who met the theoretical sampling criteria. This was designed to overcome the generally low response rate of postal questionnaires (Oppenheim, 1992). As shown in table 3, the participants represented a wide range of services, which contributed to an understanding of the multidisciplinary interpretations of living with chronic illness.

Because gatekeepers were relied upon to distribute the questionnaires, there was no way of recording the characteristics of non-respondents. The response rate at 50 % was simply calculated from the number of questionnaires sent out. This method of sampling has both advantages and disadvantages. It is a quick method that requires little input from gatekeepers other than making the questionnaires available. This can mean that participants do not feel coerced into taking part. However, there is the likelihood that questionnaires were simply left on desks and subsequently ended up in the bin, making the actual response rate impossible to calculate. A different method of distribution was used in the special school phase that involved identifying named members of staff and writing to them directly.

Special school setting

Organisational context

The project was extended following data collection in the hospital setting in order to pay further attention to the management of chronic illness at the interface between patients, carers and staff in a non-medical context. To this end, a special school was chosen as the research site since, again, it was viewed as a microcosm of the national and political developments at the time, including its commitment to multiprofessional working, through the development of shared case notes, to the explicit rejection of a medical model of caring for disabled children.

In the past, the medical model influenced the priority given to physical care over education and social development of the children, resulting in children being taken from lessons for physiotherapy or missing play-time while they received nursing care. Staff at the school claimed an explicit rejection of this organisation of care and at the commencement of the project, were adapting to new timetables and organisational priorities in which, for example, speech therapy was carried out at a time which would least disrupt the child's educational programme. Pre-selection of this school gave the study the opportunity to explore the political, academic and professional vision for special education and the effects this would have on the interface between children, parents and staff.

The special school chosen for this phase provided fertile ground for each of these theoretical concerns. The school, set in the centre of a large Northern city, employs a variety of staff from different professional backgrounds including primary and secondary years teachers, nursery nurses, a G.P., nurses, physiotherapists and social workers. The majority of staff are based within the school on a full-time basis, although others (including social workers and a G.P.) serve the needs of children around the region. The school is maintained by the city's Education Authority but accepts pupils from across the whole Northern Region. The school caters for children with a wide range of physical disabilities and associated learning difficulties. It has facilities for up to 150 pupils and has a residential Unit for up to 18 pupils who board on a Monday-Friday basis. Pupils are accepted from the age of two and a half up to nineteen and are offered a range of academic and vocational courses.

Children

At the planning stage of the project, children with a head injury were initially identified as a suitable sample group, as a result of their similarities with stroke patients in terms of multiple, complex needs requiring intervention from a variety of staff, each suffering a major health change at different stages of their lives. However, analysis of observation data revealed that the children at the selected school, of whom only 5 had a head injury, had many forms of disability, each fitting with the theoretical requirements of the study. This observation period showed the medical diagnosis to be largely irrelevant to the daily experiences of the children, which was influenced more by the types of health needs, age, learning abilities and professional support offered. The following issues therefore became theoretical sampling criteria:

1. Range of physical health needs and technological dependencies
2. Range of professional hospital and home support
3. Range in age/gender/ethnic origin
4. Range in multiple pathologies
5. Range in learning abilities

This shift in focus represented a major shift in the emphasis given to multi-disciplinarity issues at the start of the project. The adoption of theoretical sampling, within the humanistic framework discussed earlier, allowed the data analysis from the hospital phase to influence and guide the decision to focus much more explicitly on issues of chronicity and biographical aspects. The theoretical sampling criteria outlined above allowed for deeper and broader exploration of themes concerning the management of chronic uncertainty with people with varied diagnoses, varied illness biographies, and varied health needs. Fundamentally, this included but also

transcended issues of multi-disciplinarity. Certainly, this shift presented a major challenge in terms of study design, implementation and presentation of the thesis. The humanistic framework, with its emphasis on voice, reaching potential and rights and responsibilities, allowed decisions to be taken that gave primacy to the voice of chronically ill patients and their families, over the more powerful voices of staff working within organisations. For this reason, 17 children and their families with varied diagnoses and varied health and educational needs were recruited to the study.

Recruitment of children to the study

In the case of the children, informed ongoing consent is an issue that has many facets and traditionally depends on the age and understanding of the child (Eiser, 1993). In this case, Field & Morse's (1996) suggestion of using the concept of 'not refusing' became important. In practice, this meant explaining the study as widely as possible to staff, patients, and children, then requesting those who did **not** want to participate to make it known. The use of passive consent or active refusal is widely used in both qualitative and quantitative studies, largely in response to low participation rates and subject selection bias that are generated in studies that use a positive consent procedure (Griffith & Hart, 2000). Despite its wide use, few studies engage in critical analysis of the ethics of this procedure. Those that do, point to the tension between protecting children from risk and allowing them a voice and use the primacy of the child's voice as a justification for using passive refusal. In this study, letters were written to the families of my chosen sample group in which an explanation of the research was given and a form was made available for people to sign if they did not

wish their child to be included in the study (see appendix 2.1). The research team were directed by the head teacher of the school in this matter, who was concerned about maintaining a therapeutic relationship with parents by not overloading them with information and expectations concerning research, at a time when parents had been asked to participate in a number of other studies carried out by staff members. Only two parents did refuse; both were single parents and had declined to engage with the school on a number of matters, particularly failing to attend child reviews and open days within the school. For the purposes of the study, exploring the reasons for refusal to engage with services would have illuminated understanding of managing chronicity at the interface. However, several phone-calls, letters and appointments in which I visited the homes at agreed times to talk about the study but found no-one home, led to no further engagement and a reluctant acceptance that the study could not be extended in this manner.

Where parental consent was given, it did not represent consent from the children themselves who were seen as competent interpreters of their world with rights to consent or withdraw from the study at any time. The children were told by their teachers about the study and I was introduced to them at the start of classes. An observation schedule was given to each child (appendix 2.2) and they were asked to tell their teacher if they felt uncomfortable taking part in the observation phase. The interviews were conducted without chaperones, which in today's climate may seem naïve and at the very least has implications for ongoing consent. Between the ages of 8 and 17 years, the children were considered to be at an age where it was acceptable to interview them independent of any parental presence (Deatrick & Faux, 1991).

This approach is mirrored by several qualitative studies in which children were interviewed without chaperones at an age considered acceptable to do so (Sartain et al, 2000). The children may have felt threatened and unable to withdraw consent without the presence of an advocate. It was felt however, that the observation period allowed me to build up a relationship with each child to the extent where they were more than able to say if they were unhappy with any aspect of the process.

On three occasions, children stopped their interviews from proceeding, citing tiredness or feeling unwell. This was anticipated since the children had multiple health needs; the fact they felt in control of the interview process reflected the fact that consent was viewed as ongoing and that participants felt comfortable to withdraw consent at any time. Following the first interview, several (n=12) children were given disposable cameras and an information sheet (appendix 3.1) and were asked to take photographs on which to base interviews. This is discussed further in chapter 5 and was intended to allow children to express feelings and thoughts about their lives, in a safe and comfortable manner.

Informal carers

Again, the selection of informal carers was reliant on the children identifying their main caregiver. This was always a parent, a step-parent or a sibling. Analysis of data taken from the hospital setting indicated that carers often suffered ill health and this influenced the interface between patients and staff. Several carers identified by the children had other caring responsibilities and health needs, making it unnecessary to extend the study to include or exclude any carers identified by the children. Of the 16

informal carers who participated in the special school phase, there were 10 mothers, 4 fathers, 1 step-father, and 1 sister.

As previously stated, the parents of participants were contacted in order to gain consent for their child to take part in the study. Willingness to take part themselves was obviously a separate issue and letters were sent to all parents asking if they would agree to be interviewed (see Appendix 4.1). This occurred during the period when some of the children were using the disposable cameras and this had the unintended effect of bringing the study to the direct attention of parents who showed increased interest in taking part in the project. Letters were then followed up with a phone call and parents were given a choice of venue; either the school or their homes. All participants chose to be interviewed at their homes, most citing travelling distance and other caring commitments as a reason for not using school premises for the interviews. The interviews were followed up with a letter thanking them for their participation and a copy of the interview transcript.

Professional staff

As in the hospital setting, data analysis showed that children and their parents came into contact with a disparate group of professionals from a variety of organisations and this finding influenced the experiences of children and their parents in terms of co-ordination of care and proactive management of chronic illness. Use of a questionnaire was again anticipated to be the most effective way of gaining access to such a disparate group, aimed at staff who come into contact with chronically ill

children in special schools from a variety of geographical areas and a range in occupational groups as shown in table 4.

Professional group	**No. of respondents**	**No. of non-respondents**
Teachers	20	16
Nurses	5	5
Occupational Therapists	2	4
Speech and Language Therapists	4	0
Physiotherapists	6	10
Doctors	2	4
Residential Staff	1	0
Social Workers	2	2
Total	42	46

Table 4: Occupational distribution of questionnaire respondents (n=42) and non-respondents in special school setting (n-46)

Concurrently with interview data collection, questionnaires were distributed and completed by staff working in 10 special schools in the Northern Region. The sample group for the questionnaire phase was again identified via gatekeepers within each organisation who were relied upon to provide names of possible staff who met the theoretical sampling criteria. Those staff were then written to directly (letter shown in appendix 5.3) and asked to complete the questionnaires. If the questionnaire was not returned by the date indicated, a second letter and questionnaire were sent. Although this method of sample recruitment did not improve the response rate from that seen in the hospital setting, it at least allowed for collation of data about non-respondents, as shown in Table 4. This data was collated

in order to ensure an adequate distribution of occupational groups in order to explore findings in a multiprofessional context. Those with a low number of returns or names provided (namely occupational therapists, residential staff, and social workers were sent further requests to participate. No further questionnaires were completed. At 48% response rate, this method of sample recruitment had a similar success rate to the method used in the hospital phase.

Ethical integrity and informed consent

The commitment to theory generation discussed earlier, created a tension experienced during sampling decision making in terms of the desire to maintain ethical integrity while at the same time rigorously following avenues of enquiry dictated by prior data analysis. When negotiating access to sample groups, Burgess (1984) discusses *'gatekeeping'* in relation to a number of issues encountered at the commencement of this study. Initially, the researcher must decide whether to contact a person they see as having power to grant or withhold access to participants in the research setting. Because of the hierarchical nature of hospital and school organisations, the research team felt it was necessary to take a 'top-down' approach to gaining permission for access to the research sites. The first stage of participant recruitment therefore began with the project supervisors who, on behalf of the University, sought formal permission from Head Teachers and Health Authorities for the research to take place. The special school granted permission soon after contact was made, while the hospital required ethics approval before commencement of data collection. The hospital Ethics Committee initially rejected my proposal on the

grounds that there would be no tangible results on which to base action or improvement in care delivery, and, after lengthy debate couched in complex quantitative language, finally gave approval for the project to commence. The question of whether approval was based on accurate understanding of the study's aims and methods has been debated within the literature (Edwards & Haddad, 1988) and as a result, committees with multiprofessional membership are becoming widely established (Szeremeta et al, 2001). I include this discussion to emphasise that I was guided more by my own professional Code of conduct as a registered nurse and also the humanistic framework adopted in this study than by any standards set by the ethics committee in this study in terms of concepts of beneficence and non-malificence, justice and respecting a person's right to give ongoing consent and to privacy.

Research with so called inarticulate subjects such as patients and children often use concerns over informed consent as a justification for not allowing the individual voice to be heard (LaPuma, 1992). This is linked with the value judgement often made in contemporary society about the relative worth of knowledge; as Sartain et al (2000) point out, the adult 'non-confused' person generally has the dominant voice. In this study, all participants (including young children and stroke patients) were seen as competent interpreters of their world and data collection methods were designed to give each participant a voice. However, the vulnerability of these participants meant that issues of competency, disclosure and comprehension influenced ethical considerations in terms of consent and sampling decisions (Pinch, 1996). For example, during observation with Anne, an incident occurred in which

nurses washed Anne alongside a patient (not included in the study) in the next bed, with screens pulled round both patients but no dividing screen so that the nurses could work between the two patients more quickly. Anne, rather than complaining about a lack of privacy, actually reported that this contact allowed her to compare herself favourably with the other patient, thus allowing for development of the core categories of comparing and managing information. The other patient was aphasic and sadly died two days after data collection leaving me with the dilemma of whether ethical consent should have been granted and by whom in order to include this incident in data analysis. Ward staff members felt that to contact family for consent would have created further stress at an already stressful time and that the need to explore the issues revealed by the incident gave justification for its inclusion. This was consistent with the concept of 'minimal harm' (Ireland & Holloway (1996)), whereby the risks are minimal if data collection is carried out in a sensitive way and the participant's agreement is obtained where possible.

Consent from Whom?

The above example illustrates the fact that in the 'fuzzy' world that I was observing, consent could be granted or withheld at any given point for reasons known only to the participant. It was important for me to recognise this and make it clear that this was entirely acceptable to me. Several times, I was denied access to events and interactions but allowed access to others. Indeed, participants would occasionally withhold consent after the event, that is, I collected data on several rich interactions and events, only to be asked by the participant not to use that data (each of these

events pertained either to the physical bodily experiences of chronic illness or to an area of decision making conflict between the patient, carer and a staff member). Although frustrating, my agreement to this went towards the formation of trust, which in turn opened doors to me and revealed relationships otherwise out of my reach. The fact that a number of patients decided not to proceed beyond the first or second point of contact revealed the inherent tension between the researcher wishing everyone to participate or at least allowing sufficient information to analyse and contextualise refusal, and the nurse, wishing to protect the rights of the individual. The fact that participants did withdraw consent at various stages of the study indicates my commitment to creating a relationship in which participants felt they had freedom to refuse to take part and that their rights were protected at every stage of the study.

When observing patients in hospital, and children in school, as in this study, it would be impossible to gain explicit consent from every single person I met. As Field & Morse (1996) point out, *'An obsession with informed consent could end naturalistic research'* (p.86). While this was certainly true, in this fuzzy and ever changing context, it was felt by the research team, the staff in each organisation, and myself that informed consent must be sought at every opportunity if the findings were to be regarded as ethically sound. In the hospital, before observation could begin in each bay area of a ward, I approached each patient in that bay, explained what I would be doing, for how long, and gave them the opportunity to refuse to allow me to be there at any time within that time period. Ethically there was no alternative to this, and I collected useful facts and insights from these people who I

had originally seen as being peripheral to the study, but were often central to the stroke patients experiences of hospital life. In the school setting, this was more challenging, since many people came and went during the course of the school day and were therefore subject to observation. The issue then became more one of providing a friendly, open demeanour and explaining the study when it seemed appropriate. I felt it was important to be honest about my nursing background; while it may have been the case that people agreed to participate in the project in order that I might influence their care in some way, this was a risk I was prepared to take. People often expressed real interest in my background and my reasons for doing the study. To have been less than honest at the outset would be rendered these conversations artificial which, aside from the obvious moral aspect, may have negatively affected subsequent interactions.

Clearly, gaining informed consent was not a simple matter of getting people to sign the relevant form at the start of the project. I found it to be an ongoing process that demanded tact and diplomacy and above all, patience. This issue again illuminates the reflexivity of my role in the field; to those whom I chose to involve, and who then allowed me to become involved, I was a complete participant, to those who were left out of this process; I took on the role of complete observer. The ambiguous, fluctuating nature of this relationship is one that demanded an awareness of my obligations to the research as well as to my Professional Code of Conduct. The very nature of theoretical sampling dictates that hidden aspects of the study were uncovered throughout the duration of the project. The issue of informed consent was

therefore fluid and ongoing with the power differential lying on the side of the participant rather than the researcher.

Barriers to theoretical sampling

As mentioned earlier, in the ward setting I was denied access to patients until they had received a diagnosis of stroke. The peri-diagnostic period was subsequently identified as being formative for patients and families in terms of relationships with staff and perceptions of progress. The fact that I was not able to directly observe this period meant that an extra dimension was missing from the retrospective accounts given during interviews. This aspect of sampling is, I believe, pivotal to the area of diagnostically driven research; had I claimed to be interested in ward cleanliness for example, would I have still been denied access to patients at the peri-diagnostic stage? The issue of diagnosis becomes a moot point when multiple pathology is taken into consideration but is a serious concern when one considers the relative lack of studies into the generic experience of chronic illness. If so much importance is placed on diagnosis, why do staff feel the need to 'protect' patients at this time, and if it is such a crucial time for patients and staff alike, then how can we explore the practice implications of this if researchers cannot gain access to it? Questionnaire data suggests that staff found it difficult to address the anxiety and questions from patients and families at this time without being able to give specific answers. This suggests that the issue of sampling is pivotal to the exploration of chronicity, in relation to the peri-diagnostic period.

The perception held by staff that participants might find the research process stressful is perhaps indicative of their own experiences of research. The hospital had been through a period of great change and highly valued its research profile. To this end, staff had been exposed to action research studies that were designed to improve practice. Several staff confided that they found these studies intrusive and anxiety provoking as they felt they were being negatively judged in terms of their professional performance. This created a barrier to my own work that had not been anticipated and made it necessary for me to work hard at demonstrating a non-judgemental, positive approach to staff.

Termination of the researcher/participant relationship

Archbold (1986) points out the potential for difficulties in ending a research relationship when dealing with vulnerable people who may be socially isolated with few if any social support networks. For example, one mother who took part in the study reported feelings of loneliness and social isolation that were relieved by taking part in the study. At her request, interviews took place at her house and she kindly invited me for lunch on several occasions. When data collection ended, we discussed my concern about her isolation and she agreed that I could request help from the school to address these issues. Only when the woman reported that she had formed a supportive, constructive relationship with a social worker based at the school did I feel able to draw my relationship with her to a natural conclusion. I felt an obligation to her and her child that went beyond the remit of the research and only when I felt her needs were being addressed did I feel able to withdraw. This reflects my

professional background as much as the intensive, personal nature of the research. In all other cases, I was able to end contact at the end of data collection with a thank you letter. Several of the children and one patient responded in kind and invited me to stay in touch. In the case of the children, I felt that to stay in touch would have become complex in terms of defining the purpose of a continued relationship, thus making both parties vulnerable to misinterpretation. In the case of the patient, contact was maintained by letter for a period of 6 months following data collection and was eventually ended by the patient herself.

Confidentiality and anonymity

Within this study, the guarantee of confidentiality and anonymity is difficult given the small social settings in which even the slightest cues of demographic information might reveal a person's identity. The fact that all interviewees read and gave permission for their interview transcripts to be used did not deny them the right to anonymity. Therefore, pseudonyms were used and information that would make participants immediately identifiable is not included in the thesis. Similarly, the photographs taken by the children were used to encourage discussion during interviews and to include them in the thesis would render the children immediately identifiable. It was therefore agreed that photographs showing the faces of children would not be reproduced in any research report.

Conclusions

Defining, identifying and accessing the sample for this study presented a number of issues, which incorporated theoretical, practical and ethical considerations. The theoretical perspectives combined with the reflexive, inductive nature of the research questions, were considered in establishing theoretical sampling criteria which then guided more practical and ethical decisions about accessing a sample of vulnerable participants and giving them an equal voice to less vulnerable participants.

In terms of sampling decisions, theoretical sampling provided the tools to ensure the adequacy of the data in order to test and challenge rather than confirm the emerging theory. The tensions between theory generation, prior researcher experience and maintaining ethical integrity influenced and guided sampling decisions. Within this, consideration was given to the termination of the researcher/participant relationship, alongside the commitment to ensure confidentiality and anonymity.

Chapter 5

Data Collection

Introduction

The methods of data collection used in the study, namely semi-participant observation, unstructured interviews, photography, field notes and qualitative questionnaires are discussed in this chapter. A rationale for methodological triangulation is offered in relation to the diverse characteristics of each participant as well as the wide-ranging aims of the study. The development and implementation of each method is outlined in relation to the completeness and confirmation it conferred to the study as a whole. The use of these methods was intended to confer an equal voice to vulnerable participants, and their carers and staff members, in a way that drove theory about managing chronicity at the interface between these participants.

In phase one of the study, a total of 264 hours of observation were carried out with 9 patients while they were in hospital. Analysis of observation data then directed the interview schedule and a total of 18 interviews were carried out with 9 patients and 20 interviews with 10 informal carers. 21 of these interviews were held during the patient's hospital stay and 17 were carried out following discharge from hospital. A return to the observation field was made in order to explore themes emerging from interview data. These themes were used to inform the design of qualitative questionnaires which were completed by 31 respondents from a variety of professional groups.

In phase two, a total of 431 hours of observation were carried out with 17 children in the special school. Analysis of observation data again directed the interview schedule and a total of 21 interviews were held with 12 children, and 18 interviews with 16 family carers. Observation and interviews were carried out

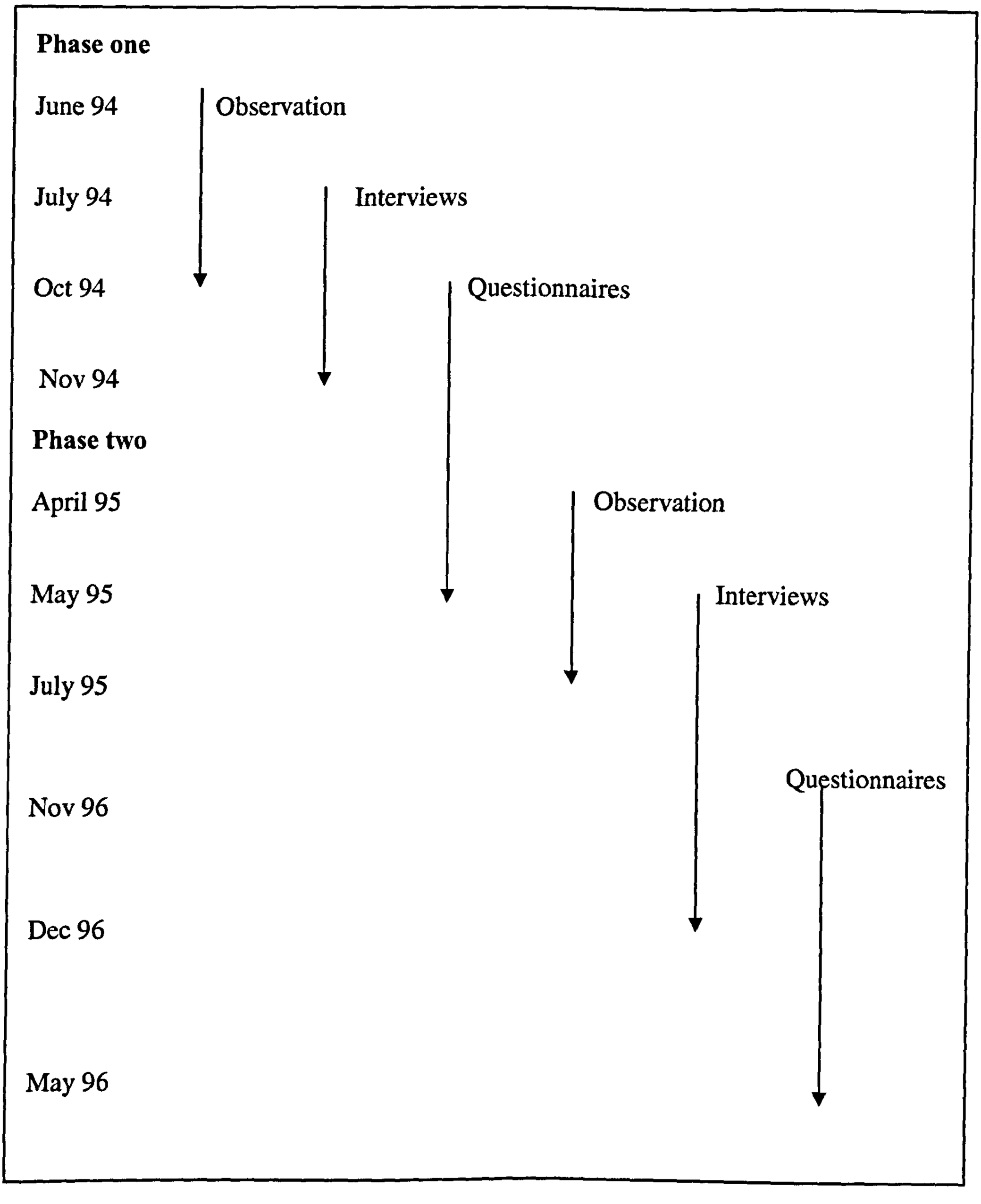
concurrently in order that a return to the field could be carried out to explore emerging interview themes. 9 children were given disposable cameras and they took a total of 216 photographs which formed the basis for interviews. Qualitative questionnaires were then designed around developing themes and were completed by 42 respondents from a variety of professional groups working in 10 special schools in the area.

In phase one, observation was carried out in order to explore the daily experiences of stroke patients in relation to the daily interface between themselves, their carers and staff. Observations moved from broad contextual data to more focused findings concerning the bodily experience of disability. Interviews with patients and their informal carers were then held concurrently with observation and focused on retrospective accounts of hospital life. The study design allowed the researcher to return to the field following interviews to explore findings more fully. This was conducive with the aim of triangulation, which is to confer completeness and confirmation on theory generation. The questionnaire collected data from formal carers and explored themes identified during earlier data collection.

In phase two, as indicated in figure 3, a similar concurrent approach took place whereby observation collected data on interactions between children, their carers and staff which were then explored during interviews with children and their informal carers. A return to the field was then made to explore themes more fully. A discussion is made of the use of photographs to engage the children in the research process. A questionnaire collected data from multi-professional staff on themes explored during previous data collection.

A description of the role adopted in the field is interweaved with an analysis of the level of access to participants and the difficulties encountered in 'going native' by the nurse/researcher.

Figure 3: Timetable of data collection in the study



Developing the observations

Observational methods are associated with a number of theoretical and methodological traditions ranging from anthropology (Spiro & Spiro, 1958), formal sociology (Frisby, 1981), symbolic interactionism (Goffman, 1971) and ethnomethodology (Heritage, 1984). Each approach aims to illuminate understanding of the depths of meaningful social experience and the underlying structure of social reality. Observational methods range from unstructured exploration of interactions (for example, Cahill, 1987, studied the role of children in public situations by writing immediate notes to be analysed later), to minute analysis of conversation and social exchanges (for example, Maynard, 1984, studied the language of courtroom negotiations using detailed, structured analysis of taped situations). Similarly, researcher roles range along a continuum from covert, complete observer when exploring behaviour in public spaces (for example, Gardner, 1988 studied navigation of physical difficulties by disabled people in public places), to 'auto-observation' in which the researcher becomes both subject and object of inquiry (for example, Ellis (1991) analyses the negotiation of meaning and identity within her relationship with her dying husband). Whichever role or method is adopted, the intention of observation is to obtain insights and accounts from a variety of participants first-hand as well as answering contextual questions which cannot be answered easily otherwise (Field & Morse, 1996).

In this study, an early commitment to ethnography resonated with the qualitative, inductive aims of the study. Interest in the three tenets of ethnography, namely, culture, naturalism, and holism provided a rationale for choosing

observation as a method of data collection that allowed for exploration of these contextual factors. An exploration of contextual features, via observation data, was necessary since this study was carried out in two different sites with contrasting contextual characteristics. Observation was therefore selected as a method on the basis that it would provide data on interactions between patients/ children and those around them in the context of the organizations in which they were cared for. This resonates with the humanistic and ethnographic commitment to both culture and naturalism. It was anticipated that this data would provide scene setting for further data collection using interviews and questionnaires. In addition, it was anticipated that observation would give access to the experiences of participants who were unable to communicate and therefore were unable to participate in interviews or answer written questionnaires.

The two main problems anticipated in using observation were; the ability of participants to give informed consent, and the effect of observation on stress experienced by participants.

Firstly, all but one patient was able to communicate in either verbal or written forms and were able to sign the consent form at some stage of the project. The ongoing, reflexive nature of consent is discussed in greater depth in the previous chapter – participants were given the opportunity to decline at all stages of the research. Secondly, the longitudinal nature of the study meant that, in phase one, all but one patient recovered their speech during the period of observation and were given the opportunity to reflect on the observation. Several patients simply accepted

my presence as a natural part of ward life and reported that it neither added to nor alleviated their stress levels.

"You do what you have to, pet. I didn't really notice what with all the comings and goings." (Joe, interview 1, phase 1)

Others, however, reported a feeling of empowerment by having a 'witness' to their experiences.

"And you are so uncomfortable sitting in one place all the time and you just can't escape the noise – it is torture – you are trapped. I think ... seeing you sitting there watching everything ... I thought 'Good' at least someone is seeing this."
(Catherine, interview 2, phase1)

Thus, observation had the potential to validate the experiences of participants in some way and enrolled the observer as an active participant in the experience.

Role negotiation

The interaction above underlined the effect my presence had in the field; rather than being a 'fly-on-the-wall', I became an active participant in peoples' lives. This highlights concerns about what has been referred to as the Hawthorne effect, defined by Polit & Hungler (1991, p. 646) as:

"The effect on the dependant variable caused by the subject's awareness that they are 'special' participants under study"

The debate about the influence of a researcher's presence in the field has raged for decades, fuelled by ethical concerns over the covert application of ethnography by social scientists who carried out studies without the knowledge or permission of participants, presumably in an attempt to minimize the Hawthorne

effect. Major distinctions are made in the literature between the different types of observation roles that can be adopted in the field, each occupying a place on a continuum between complete covert participation and complete overt observation. Historically, complete observer, either covert or overt, was the favoured role of proponents of the Chicago school of qualitative research (Adler & Adler, 1994). However, debate surrounding Humphrey's (1975) notorious, unorthodox work on homosexual activity focused not only on the ethics of covert observer roles but also on its inherent traditional ideal of the 'objective' observer. More recently, the debate has shifted interest to focus on greater involvement in the settings, and the attendant effect on power dynamics, ethics, and the types of data this gives access to. Recognition is now given to the fact that the presence of a researcher will always have an impact on those around them; participants choose to disclose subjective experiences on this basis (Hammersley & Atkinson, 1983). I share the belief that a researcher's presence is always going to affect those around them, whether their status is known or not. The tenets of symbolic interactionism bring recognition that my interactions with participants would always affect meanings and experiences, regardless of my status. Recognising and acknowledging my status and the 'effect' on participants then illuminated interactions and meanings rather than fudged them.

Adler & Adler's (1994) categorisation of observational roles proved useful in this study. They classify roles in terms of membership rather than participation in which they identify the complete-member-researcher, the active-member-researcher, and the peripheral-member-researcher. An important aim of the study was to allow for the voices of vulnerable participants to be given the same level of attention as the

voices of staff members. Complete membership, in which I would be employed as a nurse or teaching assistant was rejected since to this would formally align me with staff members, thus hindering exploration of the lived experiences of patients and children. At the other end of the spectrum, the role of complete observer was rejected in terms of the tenets of symbolic interactionism in which an observer will always have an affect on participants no matter how little interaction goes on in the field. In this study, it was anticipated that the role of peripheral-member-researcher would allow interactions during observation between the researcher and participants, which would be conducive to further data collection in the form of interviews and questionnaires.

In practice, however, it became clear that the actual role fluctuated according to the people involved and the demands of a particular situation. This is mirrored in other education and healthcare research. For example, Oakley (2000) adopted a peripheral observational role to explore the experiences of children undergoing care proceedings but reported occasions in which children would insist that she join in games or help with homework. Similarly, in healthcare, Waterman (1998) reports fluctuations in the levels of membership and participation required during a study of ophthalmic nursing. In each case, it was apparent that flexibility and reflexivity of role was vital to maintaining research relationships within the field. Opportunities for data collection were occasionally lost, but overall maintenance of the research relationships ensured a continuation of data collection.

The role adopted in this study fluctuated from peripheral to complete member, depending on the demands of a particular interaction or situation. My

primary task was to collect data which would involve observing events and interactions. Using symbolic interactionism as a guide, in which observation provided opportunities to interact with participants, I made minimal notes in the field and encouraged interactions when appropriate. At the commencement of the study, I gained permission to adopt a 'general helper' role where appropriate which might involve passing patients newspapers or giving out drinks. It was also anticipated that if a life-threatening situation presented itself, my first priority would be to the patient/child and I would be bound to assist that person within my Professional Code of Conduct. This offer of help went a long way in my acceptance into the ward, gave me useful opportunities to introduce myself to patients and their relatives, and relieved a little of the conflict I felt when watching others work on a busy ward. It was anticipated that this method would give non-threatening entry into a variety of settings in the field, the study of which would illuminate the key players, events and concepts which might become important in later stages of the study. However, this approach also had several consequences, discussed in the following section in terms of concerns about over-identification with participants, and the effect of researcher presence on the data.

Going native

Although this study is not practitioner research in the established and commonly applied sense of carrying out research in one's own organization (Reed & Procter, 1995), it shares the aim to improve practice and to increase my own knowledge base. Practitioner research is described by Reed & Procter (1995) as:

"People who are part of the world that they are researching in a way that an academic cannot be ... their commitment to developing knowledge and understanding will be motivated by their position in that culture." (p.5).

Although I had never worked in either of the organisations used in this study, I had knowledge and experience of working with both adults and children in both hospital and community settings, and in terms of the above definition, I clearly had ideas and expectations of the cultures under study that were guided by both tacit and explicit knowledge of those experiences (Eraut, 1985). The process of honestly acknowledging my status and its consequences in the field had the unexpected advantage of minimizing the process of 'going native'. This is described by Silverman (1993, p. 41) as:

"identifying so much with the participants that, like a child learning to talk, he cannot remember how he found out or how to articulate the principles underlying what he is doing."

In phase one, as a nurse, I was so conscious of remaining aware of my preconceived ideas that I was able to analyse and contextualise some of them with the intention of minimising the possibility of going native. My experience in phase two was somewhat more difficult in this regard. The setting was new to me and, at the start of observation, I felt overwhelmed by the amount of new information available to me. In addition, I was unfamiliar with the workings of the organization. In particular, I found it difficult to define my role at any particular moment, partly because I found the children so guileless and interested more in my potential as a play-mate/ comforter than in my formal reasons for being there.

An example of this occurred during the observation period; a child with Down's Syndrome insisted on sitting on my knee during story time or playtime. Falls in the play-yard resulted in hysterical calls to 'My Helen' that were only placated with cuddles and nursery rhymes. To that little boy, I was not a researcher or a nurse; I was simply a soft hearted woman who couldn't turn away from his need for affection. In addition to the head-lice he gave me (!), he also forced me to think carefully about the role I was adopting in the school and whether it was entirely conducive to data collection. In contrast to the ward environment in which roles were clearly demarcated by uniforms and badges, people I came into contact with had no way of distinguishing me from school staff unless I told them. This was compounded by the fluid, shared roles within the school, which made it easy for staff to ask me to help tidy up/ dish out meals/ read stories. While this assuaged any guilt I had at not assisting in the busy ward environment in phase one, I realised that the children had no visible, concrete way of distinguishing my researcher role from that of staff and that this may have influenced their ability to withdraw ongoing consent from someone who, in their eyes, was just another member of staff. In addition, I began to lose sight of the data; by 'going native' I certainly over-identified with the participants in the study at an early stage.

Fortunately, regular supervision sessions and peer support from other researchers made me aware of this issue and I became increasingly able to create some distance in order to make sense of the data I was collecting. One way of doing this was to cut the time spent in the field – at first, I spent all day at the school in order to gain a picture of daily routines, people and events. By gradually cutting the

time spent in the field I was able to put some actual and metaphorical distance between myself and the children that then helped them to realise I wasn't a 'regular' member of staff. The rigorous process of grounded theory analysis used within this study (described in the following chapter) also allowed me to conceptualise the data in a meaningful way that necessitated some distance from participants and gradually stopped my feelings of over-identification with the participants.

Professional value judgements

The literature indicates the potential difficulty experienced by nurse researchers in observing practice that may be of questionable quality. Koch (1994) describes the experience of participant observation on two elderly medical wards and discusses the dilemma she faced as an experienced nurse who encountered neglect and inadequate care, but who did not wish to break patient confidentiality. At the start of this study, difficulties were anticipated in relation to observations of practice. However, in both settings, I did not observe situations that could be categorized in such strong terms as 'neglect' or 'inadequacy'. The ethical dilemmas were much more subtle as the example in the previous section demonstrates. The only time I witnessed what I considered to be unacceptable care was the example in which two stroke patients were washed together by nurses working between the beds. Enraged and disturbed by this perceived lack of privacy and care carried out 'en-masse' rather than individualistically, I had difficulty in waiting to see how my understanding of the situation might improve. However, I shared Koch's concerns that if I had 'blown the whistle' I may not have been able to proceed, and would certainly have damaged

relationships with staff that I had established. I hoped that a deeper understanding of the situation might lead to improved practice in the future. Interviews gave me the opportunity to explore this further – one of the patient's involved used the incident to compare herself favourably with the other patient, and drew conclusions about her own progress and future goals. This became an important theme of the study.

Recording observation data

The intention of initial observation was to outline the broad, descriptive elements of data that would contextualise later analytical themes. These elements were mapped in terms of spatial, social and temporal dimensions described by Davis (1986). An analysis presented by Spradley (1980, summarised by Robson, 1993, p.200) was used as a framework for structuring and recording initial observation data (see table 5).

Dimension	Description
Space	Layout of the physical setting; rooms, outdoor spaces, beds
Actors	Names and relevant details of the people involved
Activities	The various activities of the actors.
Objects	Physical elements; furniture etc.
Acts	Specific individual actions
Events	Particular occasions, e.g. Formal meetings
Time	The sequence of events
Goals	What actors are attempting to accomplish
Feelings	Emotions in particular contexts

Table 5: Dimensions of descriptive observation

This framework provided a description of spatial dimensions such as the layout of wards and classrooms, and the location of physiotherapy gyms and treatment rooms, social elements such as staff membership and visitor status, and temporal information such as shift patterns, meeting times, and playtime. This process conferred structure to the collection of contextual data and alleviated the feelings I had as a neophyte of being overwhelmed by the vast amounts of data available to me. However, I found that this type of data collection relies largely on visual data gathering. Adler & Adler (1994) contend that, in fact, all other senses should be explicitly involved in gathering first impressions during observation. This was certainly experienced in this study; sitting for long periods in a smelly, hot, noisy, brightly lit 6 bedded bay was an assault on the senses in a way that influenced the time-periods spent in the field and the quality of data collected – even as a nurse accustomed to this environment, it took some time to become acclimatised and sensitive to other aspects of data. I found it necessary to explore ways in which my own experience of this environment illuminated my understanding of the patient experience before it was possible to move on to more focused collection of observations. This led to being more attuned to patient experiences of hospital life and illuminated findings concerning the fact that sitting 'doing nothing' often involved a great deal of psychological torment, loneliness, physical discomfort and emotional stress for patients. Exploiting the subjectivity inherent in the observer role therefore became an important aspect of the study.

The preliminary period of observation merged into a more focused stage in which I attended meetings, followed patients down to the stroke unit, to X-ray,

followed children to speech therapy sessions or to horse-riding sessions and was able to build up a picture of every-day life and the interfaces with staff and carers that occurred. This progressed to the final stage of selective observation in which categories and concepts were explored more thoroughly during analysis of interviews and questionnaire data.

Levels of access to participants

An important issue that was taken into account in initial discussions with gatekeepers was the access I would have to participants' interactions in terms of their physical care (for example, physiotherapy and nursing sessions). However, I had not accurately anticipated the level of access that was afforded to me in practice. A consequence of my practitioner knowledge was that staff assumed I would be capable and willing to assist with hygiene and toileting some of the younger children. I felt that to agree to such requests might not only identify me even more strongly as a member of staff (with consequences for ongoing consent), but also that this level of access to the children would constitute a form an abuse of their right to privacy. I therefore politely declined and offered to assist in a task that would free up a member of staff to carry out these personal tasks. Similarly, although several children gave permission for me to observe group physiotherapy sessions with them, I did not feel it was appropriate to ask to observe nursing care (which informal discussions with staff revealed were largely focused on hygiene and continence needs).

Likewise, in phase one, I did not directly observe personal care that occurred behind the screens although I could hear most of the interactions from my position in

the bay. Accounts of observation rarely detail the level of access afforded to the researcher – even Koch's (1994) excellent account gives no indication of the level of personal care she was given access to - and as such I was guided more by what felt 'right' in terms of the right to privacy for patients. As an experienced nurse, observing personal care holds no embarrassment for me; as a researcher, to observe such private events would have felt voyeuristic – the lack of practical focus would have made me question the ethical value of the data collected. However, this created a very real tension because of my belief, based on experience, that the interactions that occur during personal care can be crucial to the person's experience of their illness. The fact that I chose not to directly observe these interactions therefore deserves a mention. Had there been data to stimulate further interest in this aspect of the experience of chronic illness, theoretical sampling would have dictated that I pursue this further and negotiate a different level of access to patients. This would have given the observation a purpose missing from the observation period as it stood, making it less voyeuristic and more firmly rooted in theory development.

Process of observation

In phase one, 9 patients were observed for total periods ranging from 60 – 12.5 hours. In phase two, 17 children were observed for total periods ranging from 6 – 40 hours. Observation was stopped when saturation of themes was reached and therefore the time periods varied with each participant.

Observation was carried out for periods varying from 1 hour to 3 hours, as this was the maximum productive time before observer fatigue and an inability to

focus set in, and data collection was carried out at different times of day and on different days (including weekends and evenings) in order to capture an ongoing picture of participant experiences. During observation, notes were made using the above format in a small notebook which was dated and referenced. After leaving the field, more extensive notes were made which, although time consuming, became invaluable for the analysis stage. As time went on, these notes became more focused and represented data analysis in themselves, as discussed in the following chapter. Appendix 6.1 and 6.2 show an example of notes made following a period of observation and the codes that resulted from analysis of these notes.

In relation to triangulation of method, observation data complemented the retrospective nature of interviews that were carried out concurrently with observation. It did so in several ways: Firstly, information about people, places and events were clearly documented in terms of participants' experiences of the interface with carers and staff. During interviews and in the questionnaire, this later led to an exploration of the significance of events in terms of a patient's progress. Secondly, observation gave access to aspects of personal care and the bodily experience of disability that were sometimes not discussed in interviews because of their private nature. Thirdly, the time spent with participants in the field was invaluable in fostering trust, and went a long way in creating an open, honest relationship conducive to checking out categories and themes during interviews.

Interviews

Symbolic interactionism emphasizes the ability of human beings to define their interactions and shape their actions. Interviews were chosen as a method of gaining access to the retrospective meaning given to events and interactions previously observed. Similarly to observation, membership and roles during interviews vary along a continuum from formal, structured to informal and unstructured. Some authors argue that structured, standardized interviews, in which the wording and sequence of all questions are identical for each interview, have inherent validity in the sense that analytical differences in responses can be assumed to have their roots in the data, rather than in the questions asked (Price, 2002). This implies that participants share a common language and that every word holds the same meaning for every respondent. Denzin (1989) criticizes this premise and suggests that validity depends only on conveying equivalence of meaning, thus enabling the researcher to explore emerging themes.

Following initial analysis of observation data, it was necessary to identify broad areas for discussion, using a synthesis of relevant literature, my own experiential knowledge and themes emerging from observation. These were:

1. Pre-diagnostic management of symptoms
2. Management of technologies
3. Coping strategies
4. Social networks
5. Long-term aims

The tacit, intuitive knowledge held by practitioners who embark on research has several implications for the interview process. Firstly, experience of interpersonal

skills required for history taking and caregiving enabled interviews to be carried out in a way that was comfortable and relaxed for the participant. However, there was the possibility that patients may have attempted to use the researcher's knowledge or position as a nurse to a) gain information about treatment or b) to actually influence treatment. Having anticipated this issue, I had informally discussed with staff the course of action they might wish me to take. Their own course of action would be to ask the patient to write a list of their concerns to then take to a meeting with the consultant/ward sister. It was agreed that, if necessary, I could suggest the same tactics.

Interview process

A total of 18 interviews with 9 patients and 19 interviews with 10 carers were carried in phase one. In phase two, a total of 21 interviews were carried out with 12 children, and 18 interviews with 16 carers. Participants were interviewed different numbers of times varying from 1 to 4 depending on the point at which data saturation was reached. One person declined to be interviewed after the initial interview citing the fact that she was about to be discharged home and did not want any reminder of her stroke. The interviews lasted for between 40 minutes and 3 hours.

The sequence of interview topics was flexible and depended on the spontaneous direction of the interview. Initial interviews with stroke patients were short and focused very much on physical limitations and the here and now of the experience of having a stroke. Several patients were able only to give very short answers to the questions they were asked and it was sometimes difficult to grasp the

meaning of what was said as a result of the participant's speech difficulty and my relative unfamiliarity with their particular forms of speech. In addition, initial interviews with carers were occasionally very short possibly as a result of their anxiety about saying the 'right' things (Whyte, 1984). The following occurred towards the start of Ina's husband's first interview:

> Could you tell me a bit about what happened after your wife had her stroke?
> *I'll tell you whatever you want to know pet, I'm happy to help.*
> Perhaps you could start off with where you were when the stroke happened
> *Yes, pet, fire away with a question and I'll try my best. You're the expert.*

This highlights the flexibility and reflexivity that were required during interviews, and this was particularly necessary during interviews with the children who were occasionally nervous at the start of the interview and who would sometimes give one-word answers to questions. This demanded skills cited by Swanson (1986) of flexibility, intelligence and emotional security in which it was necessary to be completely focused on the interview in order to remember previous statements and seek later clarification while at the same time putting the participant at ease by using empathy and warmth. Within this, application of the inverted funnel approach, advocated by Swanson (1986) proved useful in creating a comfortable, safe atmosphere for participants whereby the interview often started with specific questions that participants were able to answer confidently and then moved on to more general questions which invited participants to speak spontaneously. This approach was particularly important in the patient and child interviews since they did not seem to feel their experiences were interesting or valuable and showed varying degrees of reflection and insight into these experiences. The fact that I showed

interest and warmth about their 'everyday' experiences came as a surprise to some. The inverted funnel approach was therefore a tool to assist movement from facts to meanings. This was consistent with the emphasis of symbolic interactionism on humans as active creators in their world. The process of moving from fact to meanings assisted this process and elicited the ways in which meanings are created and adjusted through the interactive, interpretive process.

Photo-elicitation

In anticipation of problems in getting children to articulate their own views and opinions during interviews, the children taking part in the study were asked to take photographs that were used as a focus for discussion during interviews. Photography as a method of data collection has its roots in the 'objective' ethnographic observation of rituals and cultures in which the photograph was seen as an undeniable, static record of the 'truth' of the findings of the ethnographer (Harper, 1994). Critique of this visual sociology lies in the belief that photographs "*are more precisely reflections of the photographer's point of view, biases, and knowledge*" (Becker, 1986, p. 252). This argument provided the rationale for allowing participants to actually take the pictures themselves, since it was precisely the participant's point of view and knowledge that was being explored during the interview. Harper (1994) describes this as "*photo elicitation*" (p.410) whereby the photograph is used as a tool within the interview to explore the participant's own taken-for-granted understanding of the images in order to illuminate deeper layers of data.

Commonly, studies have employed this technique using photographs taken by the researcher of the participant's world (Gold, 1991, Harper, 1987). More recently, however, participants have been asked to take photographs themselves in order to strengthen the collaborative, reflexive connection between the researcher and the participant. For example, Percy (1995) asked children from homeless families to take photographs of anything that was special to them. The effect of this was to balance the power dynamic experienced by a vulnerable, disadvantaged group and elicited themes about feeling cared for, having fun and being with special people, that the researcher might not otherwise have gained access to.

Process of photo-elicitation

In this study, photography was introduced for several reasons. Firstly, it was anticipated that children of different ages and learning abilities would show a range of reporting and reflecting abilities about their lives and experiences. Photographs were intended to stimulate discussion at a level appropriate for the child about these experiences, in a way that encouraged the child to engage with the research process. Secondly, it was congruent with the reflexive, humanistic aims of the study to balance the potential power ratio between myself and the children, who may have viewed me as an adult, authority figure; the data collected would then be simply what the children thought I wanted to hear (Whyte, 1984). The use of photographs taken by the children themselves was anticipated as a way of ensuring the exploration of issues that were culturally and socially meaningful to the child rather than the researcher. This assisted in gaining an understanding of the ways in which the

children connected their lived experience to the meanings and 'cultural representations of those experiences' (Denzin 1992, p. 74). Examples of photographs taken by participants are shown in Appendix 7.

All 12 children were asked at the end of the first interview if they would like to take pictures of whatever was important in their lives to bring to the next interview. They were given a disposable, single-use camera and an information sheet to take home and show their families (see Appendix 3.1.). Three children did not return the cameras; two children were unwilling to take part citing the fact that it was not 'cool' and would invite taunts of ridicule from friends; one child was admitted to hospital for several months and was too ill to be interviewed a second time, the camera not being used. The remaining children were keen and eager to take part. Only one child was physically unable to hold the camera steady and press the button at the same time; at his suggestion, he chose the subject of the photographs and asked a friend or carer to actually take the shot.

A total of 216 photographs were taken by 9 children. Many of the photographs were of 'special' events such as a trip to the fair, a picnic or a horse-riding trip and showed groups of people accompanying the child to the event. This allowed for discussion of the interface between the child, staff and carers and led to themes about friendship, loneliness, privacy, having fun, rules and responsibilities, and feeling ordinary. Other pictures showed 'ordinary' places in which the child spent a lot of their time, such as their bedroom, living room, garden and the residential unit at the school. This led to discussion of public and private spaces, technological equipment, being away from parents and family, and independence.

The third main category of photograph was of individual people who were special to the child. This led to discussion of friendships, comparisons of disability, prognosis, future needs, the future role of carers, family background, sibling relationships and bullying. The final type of photograph was where the child asked someone to take a picture of the child him/herself. This led to discussion of feelings about the aids used by the child, feeling ordinary or different, comparisons with other children, hopes for the future, personal likes and dislikes.

The depth and type of data elicited using photographs was both qualitatively and quantitatively better than in interviews carried out without photographs. The use of photographs therefore proved to be a very effective way of allowing children to engage with the research process in an enjoyable, non-threatening way.

The joint creation of meanings and interpretations

In both phases, subsequent interviews led to further reflection, facilitated by the fact that all respondents were sent a copy of their interview transcript before the second interview and were given the opportunity to withdraw consent for any or all of the transcript to be used. No participant withdrew consent at this stage. Physical and metaphorical ownership of the transcript seemed to give people the opportunity to further externalise their thoughts and feelings to the extent that subsequent interviews uncovered deeper layers of meaning and analysis. This resonates with Bryman's contention that interviews are not simply a means of recording 'static' data but are a process in themselves. This means that,

"*the interview becomes a naturalistic medium through which the interviewer and interviewee jointly create knowledge about subjective experience*" (Bryman, 1988, p.116).

The fact that participants articulated emotions and interpretations was facilitated by the longitudinal element of the study which allowed for reflection and testing out of observation data at subsequent interviews.

Each interview was recorded using a small tape-recorder and tapes were transcribed verbatim by myself as soon after the interview as possible. This facilitated the analysis process by allowing for preliminary analysis during the transcription process. This followed Guba & Lincoln's (1985) suggestion that theoretical sampling and constant comparison are only possible if each data unit has been transcribed and analysed before further data is collected. 90-minute tapes were used and had to be turned over halfway through. This occasionally interrupted the flow of conversation, but was easily picked up again. At an early stage of the study, the batteries ran out halfway through an otherwise productive interview, underlining to me the importance of checking and re-checking the machinery prior to subsequent interviews. In the case of the children, they were often interested in the tape-recorder itself and as well as asking to hear themselves talk at the end of the interview, they often wanted to decide where to place the machine during the interview. They were also invited to turn the tape-recorder off themselves when they wished the interview to end. This appeared to give them a feeling of control over the process. At the end of the interview, in both phases participants often continued talking about important topics after the tape-recorder had been switched off. Permission to use this data was

sought and post-contact notes were made soon after the interview, usually sitting in the car.

The setting of the interview influenced the quality of data and the power differential within the research/participant relationship. Interviews that were held in a room off a ward or in the school were stilted, short and gleaned relatively little of value. Interviews that were held in participants' own homes were much longer, with participants seeming more comfortable and more able to talk and reflect freely. This was partly due to the level of noise in each setting and the frequent unavoidable interruptions in both the hospital and the school. When carrying out interviews in the home, Swanson (1986) suggests that researcher safety should be a primary concern. To this end, I always ensured someone knew where I was going and what time I was expected to return.

Questionnaires

The intention of the questionnaire phase of the study was to collect data about staff perceptions in the context of the observed experiences of the daily lives of disabled children and adults, in order to explore 'ways in which different professional groups define their own contribution and the contribution of other professional groups in meeting defined client needs' (Chapter one, p.5). Questionnaires were chosen primarily because they were an effective method of reaching a large, widely dispersed sample in order to explore findings with a wide range of staff. Secondly, the questionnaire allowed respondents to give answers unbiased by researcher presence. Thirdly, the questionnaire assisted in the development of emerging theory

by enabling data to be collected not only on the behavioural intent of respondents but also on the assumptions underlying that intent (Blum & Foos, 1986). This was consistent with the principles of symbolic interactionism in that questionnaire data would give access to meanings and interpretations of interactions and experiences that has been identified as being important in observation and interviews.

Analysis of data from the disabled children and adults indicates that participants came into contact with many different professional groups of staff in many different environments and contexts. Observation findings suggested a hierarchical world in which staff worked in a uni-disciplinary manner but seemed to make decisions in a multi-professional way. The questionnaire allowed access to the views of as wide a range as possible of professional staff which was contextualised in terms of a) their professional groups, b) their levels and variety of experience and formal training, and c) the organisations and environments in which they worked and came into contact with clients.

In terms of construction and ease of analysis, questionnaires lend themselves to quantitative studies and are not always recognised as a tool for qualitative work. However, increasing numbers of studies now use a mix of qualitative and quantitative questions, thus gaining a mix of data suitable for theory generation. For example, in a study on the needs of wives of stroke patients, Rosenthal et al, (1993) used a self-completed questionnaire in which 27 needs statements were rated on a quantitative Likert scale. Although the focus was predominantly quantitative, open-ended questions were included at the end of the questionnaire and they elicited useful qualitative data that was used to assist in theory development.

It is relatively unusual to carry out a self-completed questionnaire in qualitative research. Far more common is the use of a questionnaire completed by the researcher during an interview (for example, Murray et al, 2001). In this study, the self-completed questionnaire was used as an efficient and effective tool in terms of time, resources and quality of data. It was anticipated that this method would give access to a large number of geographically dispersed professional staff, in a way that would have been impossible using interviews.

Developing the questionnaire

It was necessary to develop a method of summarising and describing patient and family experiences in a focused, structured questionnaire which would encourage respondents to interpret these in the context of their own insights. The literature suggested the use of case studies as a way of tapping into the experiences of the children and adults in a structured way that lends itself to the formal structure of a questionnaire. Case-studies (sometimes known as vignettes) involve brief descriptions of events or situations to which respondents are asked to react (Polit & Hungler, 1991). Many examples of the use of case studies can be found in nursing and educational research. For example, Koch (1998) used case-studies of older patients in acute care wards to explore the relationships between journaling, observing, listening, writing and rigour. Use of this method allowed the researchers to précis important experiences without losing the essence of those experiences (Field & Morse, 1996). This method is also consistent with teaching methods used widely in nursing and teacher training, and post-registration clinical supervision,

which involve the use of 'critical incidents'. Students related incidents that were particularly challenging or interesting and the group discusses the issues underlying the incident and ways of coping with similar situations. It was felt that the use of case studies would therefore be familiar to the sample group and would be appropriate for use in a questionnaire which would ask them to reflect on the case studies to ascertain their attitudes and interpretations of events and situations.

By their very nature, 'critical incidents' describe real events and situations and as such, it was tempting to use real life case studies of participants in the questionnaires. However, the amount and type of information included in the case-studies in most cases rendered the participants recognisable, thereby compromising my promise of anonymity. In order to retain the 'essence' of the lived experiences of participants, case-studies were constructed as a separate amalgamation of data collected from the children and adults in a way that conferred anonymity but also reflected reality in order that respondents could relate to the descriptions in terms of their everyday work. Figure 4 shows a case study taken from the questionnaire sent to special schools:

Figure 4: Case study A taken from phase two questionnaire

Simon is a 13-year-old boy who lives with his parents and his 5-year-old sister in a terraced council house. Simon attends a special school near his home. Simon's father suffers from arthritis and is partially deaf. He does not work but takes the children to and from school and does the housework. Simon's mother works full-time in a bank. Simon has cerebral palsy and is partially deaf. He has mild learning difficulties and he finds it difficult to concentrate on a task for more than five minutes. Simon is often aggressive and uses his electric wheelchair to bang into, and injure, other children and staff. He has control over his bladder and bowels but is occasionally incontinent. He has limited control of his hands and uses a communication keyboard to overcome his speech difficulties.

Piloting the questionnaire

Robson (1993, p.243) states that,

"For the results to have any hope of meaningfulness, the questionnaire must be painstakingly constructed, with very clear and unambiguous instructions, and careful wording of questions.".

With this in mind, the questionnaire was piloted (n=9) before being sent to the sample group (see appendix 8.1) and was developed using Oppenheim's (1992, p.121) advice,

"the focus and contents of the questions must be right; second, that the wording must be suitable; and third, that the context, sequence and response categories must help the respondent without unintentionally biasing the answers."

The pilot questionnaire asked closed, structured questions about the case-studies and gave several alternative responses from which the respondent must choose one. This was piloted with obliging colleagues and professional acquaintances from varied professional backgrounds including social work, medicine and special needs teaching. This pilot was invaluable since it showed the questionnaire used nursing and medical language clearly inappropriate for distribution to a multi-professional sample group. In addition, each respondent interpreted the closed, focused questions in very different ways. Respondents reported great frustration at the lack of space available to them and also the demands put on them by these open questions which they had difficulty in interpreting, thus creating anxiety about the response expectations I might have. The pilot resulted in the use of both open and closed questions, the order and construction of which followed guidelines given by Seaman

(1987) and Oppenheim (1992). Appendix 8.2 and 8.3 show the final result that was distributed to 10 NHS Trusts (A) and 10 special schools (B) in the Northern Region.

Firstly, Seaman (1987) suggests that the content of the questionnaire must arise solely from the research problem and proposal. In this study, the questionnaire was designed to elicit views on respondents' roles and the roles of other staff in the context of every day experiences. Therefore, the questions focused on the professional contribution that might be made in the care of the child or adult, the immediate and long-term aims of care and education, and what might be done about specific issues identified in the case studies. In the context of grounded theory, these questions were constructed following analysis of data on the lives of disabled children and adults and focused on issues identified in the aims of the study namely:

1. Uni-professional management of the patient/ child's needs
2. Multi-professional aims of care
3. Present aims of care
4. Long-term future aims of care
5. Needs of informal carers

Secondly, Seaman recommends that the wording of questions show clarity, brevity, simplicity, and applicability to the study sample. The pilot samples assisted with this process of eliminating ambiguous words and phrases such as 'care' and 'treatment' that were biased towards medical and nursing respondents.

Thirdly, both Seaman and Oppenheim underline the importance of giving attention to the order of questions and suggest that questions should precede from general to specific, regardless of whether the question is open or closed. This funnel approach served to focus the mind of the respondent and tried to ensure that they did

not lose interest in the questionnaire. Simple, general questions were asked about professional referral mechanisms before moving onto more focused questions about the aims of care and specific courses of action for each case study.

Implementing the questionnaire

Seaman (1987) suggests that it is important to send the questionnaire with a covering letter to a named person as opposed to carrying out a general mail shot to an organisation in the hope that the questionnaires will not sit for weeks on someone's desk. This was done by contacting each department by telephone to explain about the study, to find out the name of the head of department and to ask them to pass a certain number of questionnaires on to members of their staff. This required quite a high level of commitment from these heads of department and 4 weeks after the initial contact, a follow-up letter was sent with further copies of the questionnaire. There could have been several reasons for the poor response rate (50%) in phase one. Firstly, as already stated, the distribution strategy required a high level of commitment from head of department. Secondly, the very fact that managers were asking staff to complete the questionnaire may have been seen by staff as yet another unwanted task imposed from above. In addition to this, the use of managers in this way may have introduced some bias in the information they relayed to staff about the study and in the fact that staff may have believed that their answers would not be kept anonymous from their managers.

A second round of questionnaires were sent out which targeted social workers and occupational therapists (where the response rate was particularly low) but

unfortunately, no more questionnaires were returned. This called for a change of tactics in the special school phase of the study; once I had identified the relevant head of department at each school, I sent him or her a form asking for names of members of staff from each professional group who they felt might be willing to take part in the study. I then wrote to each of these named people directly and sent them a copy of the questionnaire to complete. The fact that I had written to them personally, thereby reducing the risk of bias through their manager, did not appear to influence the response rate which was 48% compared to 50% in phase one.

Some of the respondents gave extremely thoughtful and full answers to the questions and had probably spent at least an hour completing the questionnaire. Their responses were not just lengthy but were sufficiently complex and detailed to warrant different categories so that multiple codes and categories arose from one sentence or paragraph. The analysis was carried out in the context of the aims discussed earlier with particular reference to:

1. The ways in which different professional groups define their own contributions in meeting client needs.
2. The ways in which respondents define the contribution of other professional groups in meeting client needs
3. The working relationships between clients and staff and between informal carers and staff
4. The interpretations made by staff of needs and progress

Triangulation of methods

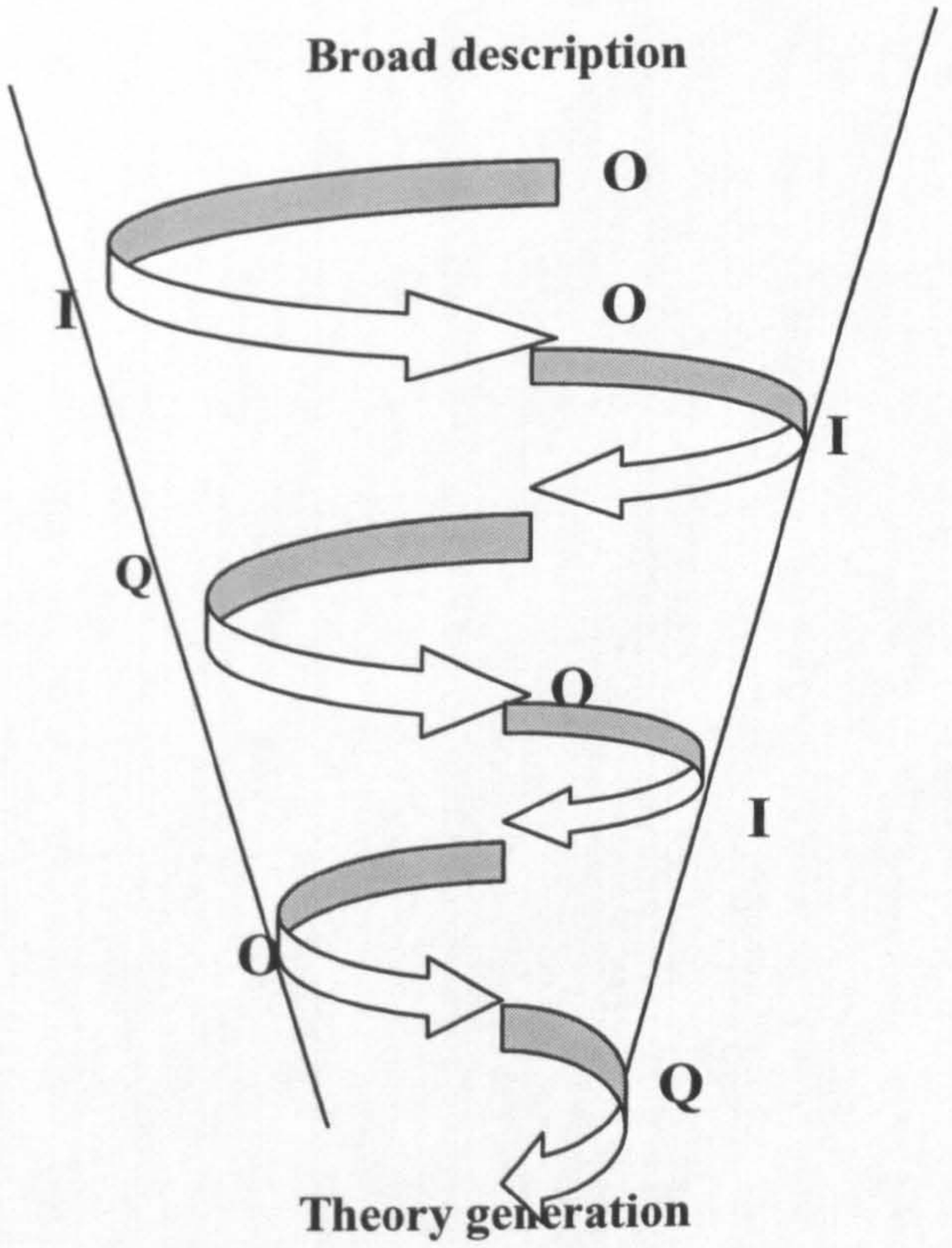
The methodological triangulation adopted within this study is discussed in this section in relation to its dual application for confirmation and completeness of findings. The reasons for this study design were two-fold; firstly, the cyclical nature of data collection in this study allowed for theory testing of emergent categories and codes which minimized the effects of bias by allowing testing of categories in different contexts using different methods. Adler & Adler (1994) contend that this triangulation of methods confers rigor to the data collection process where confirmation or data convergence around a theory is upheld (Yin, 1994).

Secondly, in relation to reliability, being able to return to the field and carry out observation in varying conditions over time, ensured a wide range of what Adler & Adler (1994) refer to as 'observational consistency' (p.318), in which categories were tested over time in two different settings. Nolan et al (1995) demonstrated this in an observational study on activity and interaction levels amongst elderly patients in care in which observation was carried out at different times when the care setting was busy and then quiet, and in different care settings with contrasting approaches to providing purposeful activities. This time and place sampling gave depth to findings, which contributed to the debate about neglect of psychological well-being of elderly patients who find themselves in a care setting.

In this study, observation gave access to activities and interfaces over time in both an acute and a chronic setting, patient interviews put these interfaces in the context of strategies for dealing with uncertainty, staff questionnaires explored the management of the illness trajectory within and beyond the experience of

uncertainty. The purpose of methodological triangulation here is completeness, in which a method is chosen for its unique contribution to the research aims and assists in the development of theory (Bergen & While, 2000). In terms of the types of data collected in the field, Spradley (1980) and Jorgensen (1989) envisage stages of observation forming a funnel moving from descriptive, broad questions (concerning routines, rituals and participants) and becoming progressively narrower towards the codes and categories that will drive theory. In this study, a cyclical process was designed to occur within this analytic funnel, as shown in figure 5, whereby project design allowed for exploration and cross checking of interview (I) and questionnaire (Q) data by going back into the field and carrying out further observation (O) and interviews to explore emerging categories.

***Figure 5*: Cyclical data collection and analysis**



It was anticipated that this triangulation of methods would allow for exploration of themes from the viewpoint of all participants in a way that allowed for both confirmation and completeness of findings, thus conferring credibility and rigor to the study (Yin, 1994).

Discussion

The study used the qualitative data collection methods of observation, interviews and questionnaires in a way that was consistent with both the symbolic interactionism and humanistic tenets of the study. Phase one of the study collected data from stroke patients using observation and interviews. Observation proved to be very effective in illuminating the bodily experience of disability, something which has received little attention in disability literature (Shakespeare & Watson, 1998). It also gave valuable contextual information about people, places and events that were later used to contribute to a complete picture of participants' lives. The data obtained from interviews with patients and carers proved substantially different from that obtained during the observation. Interviews became a medium through which participants were able to reflect on their lives, often in a way they had not done so previously. Questionnaire data then gave staff the opportunity to add their voice to the picture of the interface between patients, carer and staff.

In phase two, observation served to build relationships with children that were conducive to interviews based on trust and safety. This process was facilitated through the use of photographs. These were extremely valuable in allowing the children to engage with the research process in a way that balanced the power

dynamic between the child and the researcher. Interviews based around discussion of the photographs elicited rich data concerning 'special' events, ordinary lives, social networks and perceptions of self and others. Questionnaire data from staff gave the opportunity to place previous data in the context of multi-professional aims of care.

Chapter 6

Data analysis

Introduction

This chapter describes both the intellectual and physical processes that were undergone in managing the analysis process. Grounded theory informed and guided decisions at each stage concerning the management of data and the need to collect further data. The intellectual process of categorising and making sense of the data is presented as a challenging task that allowed for movement from a general content analysis through to a more specific thematic analysis grounded in the aims of the thesis. This process was assisted by the structured method of enquiry offered by grounded theory in terms of coding the data. The process of physically managing the data was assisted by the use of memos and diagramming. This allowed for the emergence of a core category and the development of a theory that is firmly grounded in the data.

Knowledge generation

In this study, the grounded theory method for analysis was selected as it allowed an inductively derived theory to emerge that was firmly grounded in the data. This was consistent with the aims of the study that intended to understand the ways in which participants attached meaning to their world and interpreted their relationships and experiences with others; in particular with the multiprofessional team and their informal carers, as well as with other people with whom they shared the care setting. In the current study, this provided an analytical approach that led to the development of the theory of embracing uncertainty at the interface between clients and carers.

The early work of Glaser & Strauss (1967), in their book 'The Discovery of Grounded Theory' initially presented itself as being linear, fixed, and couched in the positivistic language of variables and properties. This created dissonance with my early commitment to reflexivity, creativity and fluidity. This dissonance was mirrored in debates concerning the nature and process of carrying out grounded theory, not just in terms of data analysis, but also in relation to the level and depth of the primary literature review, sampling decisions, and data collection. For example, early grounded theorists suggest carrying out the bare minimum of a literature review at the start of a study in order that analysis is not influenced or guided by prior knowledge (Stern, 1980). However, it became clear that more recent opinions can be located on a continuum of the relationship between prior knowledge and theory generation. It seems that the work of students of Glaser & Strauss (for example, Chenitz & Swanson, 1986, May, 1996; Stern, 1994), and more recently, students of those students (for example, Eaves, 2001) represent far more than secondary sources

to the original tenets of grounded theory. As Keddy et al (1996) point out, the evolution and constant re-defining of the principles and process of grounded theory can be seen in the work of these writers, represented in debates concerning the influence of the researcher over the development of theory. In particular, theory is not simply seen to emerge from the data, but is regarded as a creative product of the interaction between the researcher and the data via a fluid process of data analysis (Keddy et al, 1996).

In this study, prior knowledge of the setting was not a barrier to using grounded theory and in fact is recognised as valuable and utilised in terms of 'theoretical sensitivity' by Strauss & Corbin (1990, p.42). A number of sources are recognised as providing sensitivity to and knowledge of the area under study, namely, the literature, professional experience, and personal experience. The grounded theory method conferred a transparency and clarity of process that located previous experience and theoretical debates but did not use these to determine the research questions. Grounded theory enabled the identification of novel issues and phenomena in the research setting to be identified and included in the study that were grounded in the experiences of the participants, but also to include and test out the wider macro societal debates for their validity within the context of the data collected. The processes involved in collecting and analysing the data are the subject of the following sections.

The commitment to symbolic interactionism allowed for analysis to focus on the participant triad, namely the interface between people with chronic illness, their

informal carers, and formal carers. From this, a number of areas formed the basis for a grounded theory analysis:

1. The interface within the triad.
2. The interface beyond the triad:
    - Interactions and experiences shared between different people with chronic illness in the care setting.
    - The interface between formal carers from different professional groups
    - The interface between people with chronic illness and other people's informal carers.

Constant comparison

Inherent in the grounded theory approach is the idea that data collection and analysis occur concurrently during the study in such a way that allows each to inform decisions about the other. This is expressed in the theoretical sampling decisions in which analysis and theory generation informed subsequent sampling, as discussed in chapter 4. At a more micro level, analysis of data informed data collection within sample groups, so for example analysis of an interview led to the refinement and focus of questions in subsequent interviews.

Several authors, for example Burnard (1991) recommend that coding and categorising is done by a second and even a third person in order to confer validity and to uncover further categories and data sets. This suggests that the goal of analysis is to produce a static, objective, generalisable truth. This option was rejected in the present study since the longitudinal, reflexive nature of my approach could not be validated by any other person, even supposing they had undertaken the same

observation and interview stages at the same time as myself. These stages influenced the development and analysis of the questionnaires and to have a second coder would have negated the process consistent with the grounded theory approach in which analysis begins the moment that a period of data collection ends. Constant comparison then allows a cyclical approach to analysis as advocated by Hammersley & Atkinson (1995) in which analysis of initial data influences and guides further sampling and data collection. This approach was entirely consistent with the tenets of symbolic interactionism discussed earlier in that the analysis and subsequent findings cannot be separated from engagement in the process of jointly creating meaning via a process of data collection.

The process of constant comparison had the advantage of allowing me to return to the data and refine questions, develop ideas, and pursue emerging phenomena. However, I had underestimated both the vast amount of data, and the time it would take to handle and analyse this data. The simplicity and ease with which analysis is presented in the literature did not reflect its ambiguity about how to **physically** manage the data, as opposed to **intellectually.** Qualitative studies have been widely criticised for being less than transparent in these areas (St John & Johnson, 2000), and ironically much of the process of data analysis has been likened to intuitive or tacit knowledge inherent in areas that lend themselves to qualitative study (Smith & Biley, 1997). Fortunately, grounded theory has the advantage of generating prescriptive accounts of both its nature and process, with increasing numbers of authors offering detailed accounts of the analysis process in their studies (for example, Eaves, 2001; Fenwick, 2001). The following section discusses the

physical handling of the data followed by a description of the more intellectual process of coding and categorising the data.

Observation

With regard to the observation phase, notes were taken using the proforma shown in appendix 2.2. Extensive notes were made during the observation where possible and further notes were taken immediately following the period of observation. All notes were then typed and managed in the same manner as the interview transcripts.

Interviews

With regard to the interview stage of data collection, Becker (1993) recommends that analysis starts immediately after the interview in the form of notes and theoretical memos. This was carried out where possible but because of the demand on space in both the hospital and school, I was often required to vacate the room where the interview had taken place and carry out initial analysis on return to my office. The tapes were listened to and checked for sound quality. In one instance, the sound quality was so poor that the tape was destroyed and detailed notes were made from memory. The tapes were then transcribed verbatim by myself rather than an audio-typist partly because I wanted to remain as close to the data as possible and also because this gave me an opportunity to record non-verbal communication whose meaning was inferred by myself at the time of the interview.

Questionnaire

The questionnaire contained two types of questions; statements with pre-coded response options and open-ended questions asking for qualitative comment. The statements lent themselves to quantitative analysis and although a data handling system such as Excel or NUDIST would have been applicable here (Fielding & Lee, 1996) I felt that time and energy spent learning to use the computer packages would have been a distraction from the 'real' work of analysis. I worried that the use of technology would remove me from the process of understanding my data and might lead to an uncritical acceptance of categories generated (as discussed by Sandelowski, 1993). However, with hindsight it is likely that the use of a computer package would have saved time in performing manual tasks and more importantly, may have assisted to remain clear and explicit about the process of data analysis even after a long period of time.

Memos and diagrams

Much of the literature (Glaser, 1992, Robson, 1993) advocates the use of memos to record thought processes and analytical explorations of codes and categories. Memos were kept throughout the duration of the study and to the present date and were useful in terms of recording my ideas about relationships between emerging codes and categories. Some of the memos were self-reflective and allowed me to track my own intellectual and professional development as a researcher, as well as the development of the analysis itself. These memos (appendix 9.1) proved invaluable both at the time of preliminary analysis but more recently, they provided a memory

prompt and a 'map' on which to base further analysis when returning to the data. They then provided the basis for the writing of this thesis.

Diagrams were used at all stages of the analysis to explore relationships between codes and categories and their relationship to the core categories. Again, I worried that computers would remove me from the data and found a pen and large pieces of paper more useful in creating meaningful and flexible analytical tools. Strauss (1987) advocates the use of diagrams in order to stimulate and clarify implications of the emerging knowledge and gaps in that knowledge.

Categorisation of data

Initial analysis of qualitative data is commonly concerned with the reduction of data into meaningful units (Miles & Huberman, 1984) or 'fuzzy categories' (Pope et al, 2000, p.114). Exploration of these units leads to the process of convergence in which data is classified into mutually exclusive categories. Categories are then 'saturated' (Corbin, 1986); at this point no further variations or characteristics are found within the data. The theory then emerges from the resultant categories.

A key feature of indexing the data into codes is that it is inclusive; that is, codes are added "*to reflect as many of the nuances in the data as possible, rather than reducing the data to a few numerical codes*" (Pope et al, 2000, p.115). Paradoxically, this **inclusive** approach should then lead to codes which are mutually **exclusive**; in this way, the data has been exhausted. The process of categorising the data generated many codes such as boredom, trade-offs and anger; these are shown in Appendix 9.2 and 9.3. However, this content analysis gave no feel for the thematic

analysis that was to come and the 'story' of participants was lost in a whirl of codes. This problem is discussed by Seidel (1991) who expresses concern that codes become objects divorced from the context and therefore their relative importance within the data. In other words, in my attempt to achieve mutual exclusivity, each code was given equal status, thus resulting in a lack of control and loss of perspective over the relevance of any particular code to the emerging theory. This position is mirrored in a number of studies that demonstrate interesting thematic findings but do not give any indication of the links between themes, a fact explicated by Benoliel (1996) in her analysis of 146 grounded theory publications. This under-analysis of data leads to 'premature closure' (Eaves, 2001, p. 657), which then prevents movement to higher levels of conceptual interpretation. In this study, using codes and categories and exploring the links between them assisted me to construct an analysis of the data in order to overcome these difficulties. Grounded theory analysis offered a way to overcome the fog of ideas and codes I had initially developed; in which the codes are merely tools that can be changed or worked back and forth between the original data and the emergent theory. The following section discusses how a grounded theory approach to data analysis assisted the researcher to move from simple content analysis to a meaningful emerging theory during what I refer to as secondary analysis.

Grounded theory analysis

The fact that several methods of data collection were employed in this study meant that any data analysis approach would need to be capable of synthesising thematic

analysis of different types of data collected in a variety of ways in a variety of settings. As discussed in chapter 3, grounded theory encouraged and gave structure to the intellectual enquiry required in this study which provided a means of adding a layer of abstract, theoretical analysis to the thematic analysis already carried out.

Coding the data

When starting data analysis, Strauss & Corbin (1990) distinguish between open, axial and selective coding. Coding initially involved a word by word, line by line, examination of the data and assigning data codes that reflected the meaning of the participant's words and phrases. These 'open' codes are an attempt to answer the question 'what is happening here?' and far from being a summary of events, they represented a first attempt at conceptualising the data. In this study, this move from summarizing to conceptualising was reflected in the fact that at first I used 'in vivo' codes, that is words and phrases actually used by participants (Glaser, 1978, p.70); for example, *"keeping in with the docs"* (Ina, interview 1, phase 1). As I began to think more intellectually and analytically about the data, codes were assigned that reflected a more abstract concept (for example, 'role negotiation'). These codes were recorded on index cards, with a short description or quote taken from the text, and a note of its position in the text.

The codes that were generated during this process were then subject to further analysis in order to identify categories within the data. Codes were examined using the two analytic procedures identified by Strauss & Corbin (1990), namely the "making of comparisons" and "asking of questions" (p.62). Grounded theory is

described as the constant comparative method of analysis in much of literature since it is this process that allow findings and theory to be grounded in the data from which it originates. The process of comparing incident with incident within the data allowed for the exploration of whether codes simply represented different names for the same phenomenon, or whether in fact they were different. This 'axial' coding then led to an exploration of the properties of each code in terms of their relationship with each other and also how they contributed to the emerging categories. For example, the code 'boredom' was considered in terms of degree, location, duration, causal factors and consequences. It was compared with other codes such as 'goal setting' and 'motivation' and this led to the development of the category 'restoration'. As this process continued, the number of cards rapidly expanded, and it enabled identification of coded phenomena that recurred in the data. From this, subcategories were identified that represented dimensional aspects of categories.

Core category and theory generation

The final, most challenging stage of analysis involves integrating the categories and selecting the core category to form a grounded theory. Again, this process involves comparison between categories in order to explore how the core category relates to other categories and to identify gaps where further refinement and development is needed. This process was challenging on two levels; firstly it involved committing to a story line at a time when all I could see were codes and categories; and secondly, inherent within the story there needed to be an exploration of process. Strauss & Corbin (1992) suggest that the researcher take a step back at this point and try to

record in a few sentences the 'essence' of the story. I was encouraged to carry out this in a similar way by a research supervisor who asked me what my reply would be to a person running for a train who asked what my findings are. This process was useful as it made me return to the data and recall what the main areas of concern had been for the participants themselves. Their concerns about making sense of the illness trajectory and managing the transition from an acute, curative model to a chronic restorative model, via a process of coping with uncertainty had been lost in my search for an exhaustive list of codes.

The emerging theory of embracing uncertainty then required an exploration of process to complete the analysis. However, during this analysis it became clear to me that **three** core processes, not **one** (as so often indicated within the literature) were running alongside each other, equally distinct and important to the emerging story, each relating to all other categories. The **cyclical** process of sense making and dealing with uncertainty became a core process undertaken at each stage of the **cyclical** sense-making trajectory categorised by a **linear** acute/chronic experience of the illness. A return to the recommendation made earlier (Glaser & Strauss, 1967) about returning to the data to fill in the gaps led to the conclusion that these processes and categories all contributed to the overarching theory of adapting to uncertainty at the interface between clients and carers.

Early attempts to present this theory in a meaningful way led to analysis of the links between theory generation and practice development, the relationship between the researcher and the development of theory, and the tension between the need for a linear presentation and of demonstrating the circular, fluid process that

defines constant comparison. My quest for clarity seemed to introduce a rigidity that did not allow for the exploration of negative cases within the data, nor for an exploration of the implications of the theory for practice development. For example, the basic social process identified within the theory is making sense of uncertainty at each stage of the illness trajectory, which culminates in acceptance of chronicity. However, several negative cases in which this final stage was never reached, led to deeper analysis of strategies for dealing with uncertainty that could not easily be depicted without appearing to contradict the emerging theory. These contradictions appeared to be as important for theory generation and practice development as those data that fit easily into the theory. This, I believe, is an inherent problem with grounded theories, and indeed with all qualitative research and is evidenced by the work of Eaves (2001) who presented a grounded model of rural family caregiving for elderly stroke survivors. In this, she presents an interesting and meaningful model that depicts the strategies used by caregivers in managing transitions through a series of stages from deciding to care, through to coming to terms with relinquishing care. While aspects of this linear process resonated with my experience of caregiving, as a practitioner, I am just as interested in those people who failed to move through the process towards its resolution and the interactions and interfaces they encountered on the way, since it is often these negative cases that illuminate the experiences of participants in a way that can be translated into practical applications.

Consideration of these issues led me to revisit the literature on grounded theory. It seemed that the split between the authors Glaser and Strauss lay in the tension between the 'fit' of the theory to the problem under study, and 'emergence'

of the theory from the data. According to Stern (1994), Glaser required the theory to emerge by asking 'What do we have here?' and would expect the theory to be applicable to, and testable by, people who shared the problem under study. In contrast, Strauss is interested in the development of the theory in relation to contextual facts that could relate to the data, whether they appear in the data or not. He interrogates the data by asking 'What if?' and therefore downplays the importance of its applicability. Having previously seen this argument as esoteric with little resonance with the pragmatic process of my study, I began to realise that this debate lay at the heart of my concern for producing a meaningful theory that might influence practice in some way. I now realise that my emerging theory leans towards Glasarian interpretation of grounded theory in the sense that it should be applicable and easily testable in the practice arena if the theory is to develop and have any resonance with the experiences of participants. However, the very fact that this was a study involving two very different settings required an analysis of context, thus sharing elements of the Strauss interpretation of grounded theory. Although this dichotomy of interpretations is often presented as being conflicting and mutually exclusive, I share Cutcliffe's (2000, p. 1483) view that using a combined approach "*would provide a richer and more complete understanding*". To this end, I revisited the analysis and it seemed that it was possible to present the theory with its negative cases and contradictions, in order to further illuminate the interface between patients, formal and informal carers. It seemed that this approach made the theory resonate with practice and with the experiences of participants (as in Glasarian interpretation), but that this was only possible by adding contextual, Straussian data about the acute,

medical model of the hospital setting as compared with the chronic, restorative model evidenced within the special school setting.

This debate is evidenced by discussion of the two models that arose from data analysis. Figure 6, below, shows a linear trajectory of stages in which participants used strategies in order to make sense of their underlying uncertainty about the trajectory and its affects on their lives. However, this did not depict the triad interface, the movement from an acute to a chronic model of care, or the fact that participants could move back a stage, dependent on conditions of conflict that are identified in figure 7. This model, although essentially the same as figure 6, seems to reflect the data in a way that would make it more three-dimensional and therefore applicable to the practice arena. Using this model as a template to gain better mastery over the presentation of the data, I will present the three findings chapters in order of the three interwoven processes evidenced in the model, namely, movement along the illness trajectory (which involves the patient journey), movement from uncertainty to sense-making (which involves the patient and the family), and movement from the acute, curative paradigm to the chronic, restorative model (which involves the interface between patients, family and formal carers – thus completing the triad), all of which culminate in acceptance of chronicity.

***Figure 6*: A preliminary model of making sense of the illness trajectory for people with chronic illness and their formal and informal carers**

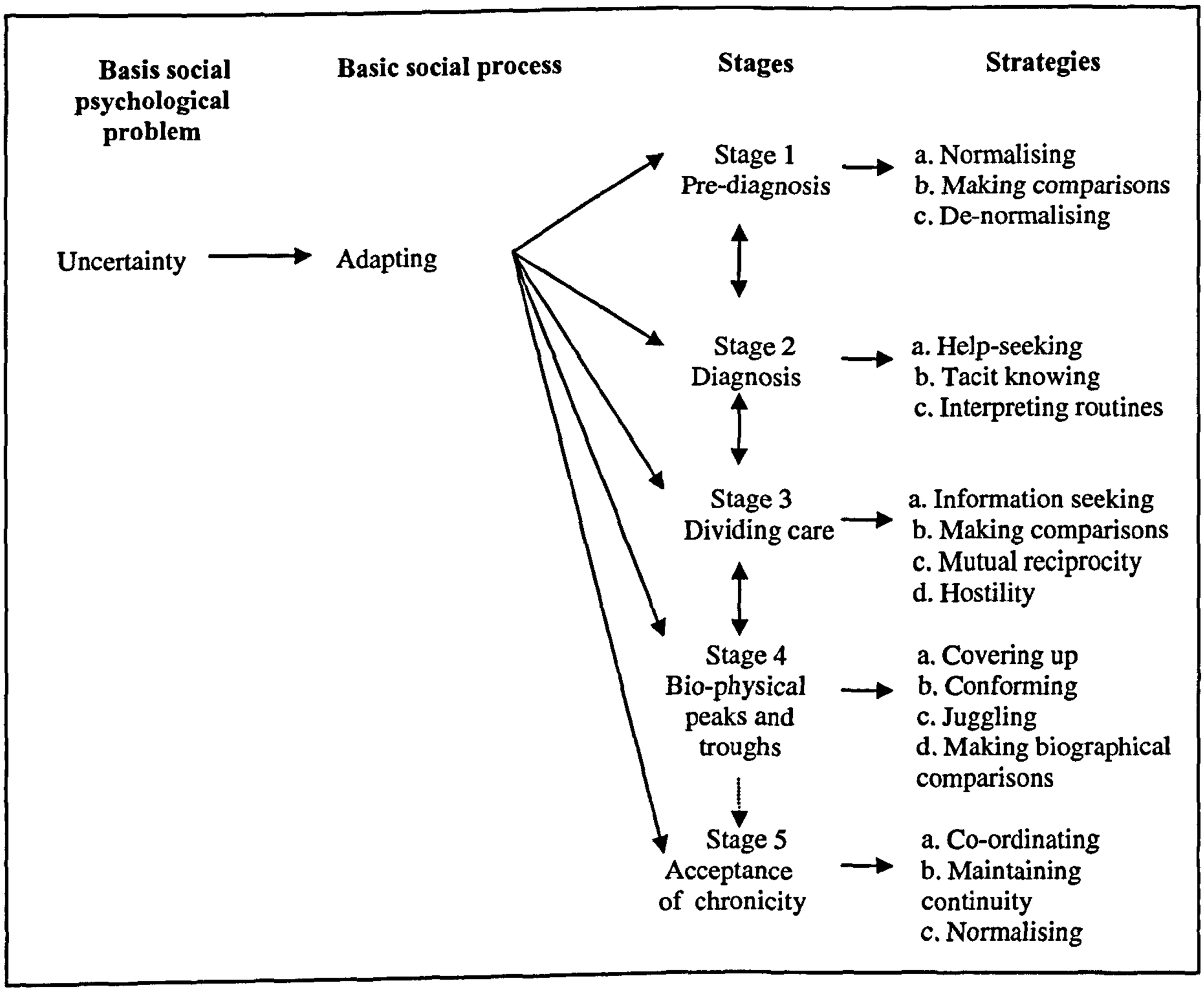
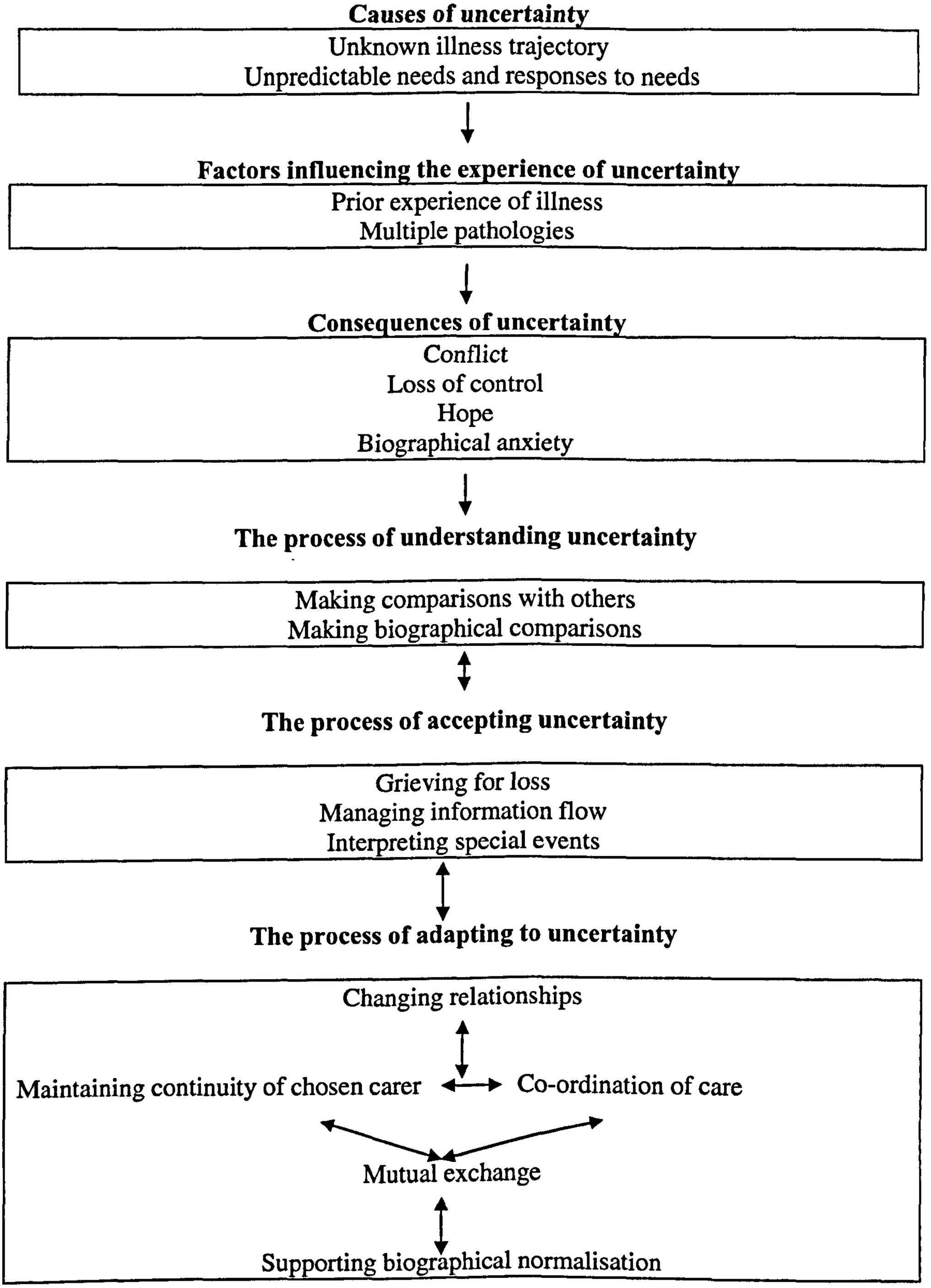


Figure 7: **A model of the theory of living with uncertainty**



Conclusions

This chapter has outlined the ways in which the grounded theory approach defined and guided the focus of analysis. This analysis focused within and beyond interactions at the interface between the relationship triad under study, namely the relationship between people with chronic illness, their informal carers and formal carers. The reflexive, joint creation of meaning in this study made it necessary for a rigorous analysis process that evidenced the decision trial taken during this study. This was particularly necessary since analysis was done with no outside observers and may have been subject to bias and manipulation in relation to my own interests rather than those of participants. Grounded theory techniques provided tools for managing the data both physically and intellectually that allow decisions to be challenged and rigorously explored at every stage. This was enhanced through the application of constant comparison in which codes and categories were explored by revisiting the data to check their importance and meaning with participants.

The approach taken within grounded theory then allowed for the testing out of the emerging theory in terms of criteria offered by Strauss (1987). This was consistent with the commitment to trustworthiness and honesty in this study.

Chapter 7

Dimensions of Uncertainty: Causes, Consequences and Influencing Factors

Introduction

Adaptation to uncertainty is the core psychosocial process identified in this study. The process of adapting to uncertainty is presented as the way in which the chronically ill person and family define their relationship with the illness, with each other, and with professional staff. In this study, uncertainty in chronic illness is defined as: the inability to understand, predict, or control, the causes, consequences, or responses to changing physical and psycho-social needs over the course of an illness trajectory. Adaptation is defined as: The ability to understand, accept and adapt to the causes, consequences and responses to changing needs over the course of an illness trajectory, using strategies that confer understanding, prediction or control over the uncertainty experience.

The central argument of this thesis is that successful adaptation to uncertainty resulted from a subtle interplay between the strategies of making comparisons, normalising, mutual exchange, and information management. Use of these strategies led to an acceptance that uncertainty could not be eradicated from an illness trajectory that was inherently uncertain, unpredictable but ultimately chronic in nature. Failure to adopt these strategies are rooted in conflict between patients, carers and professional staff and led to poor co-ordination of care, and an inability to accept or adapt to the uncertainty across the illness trajectory.

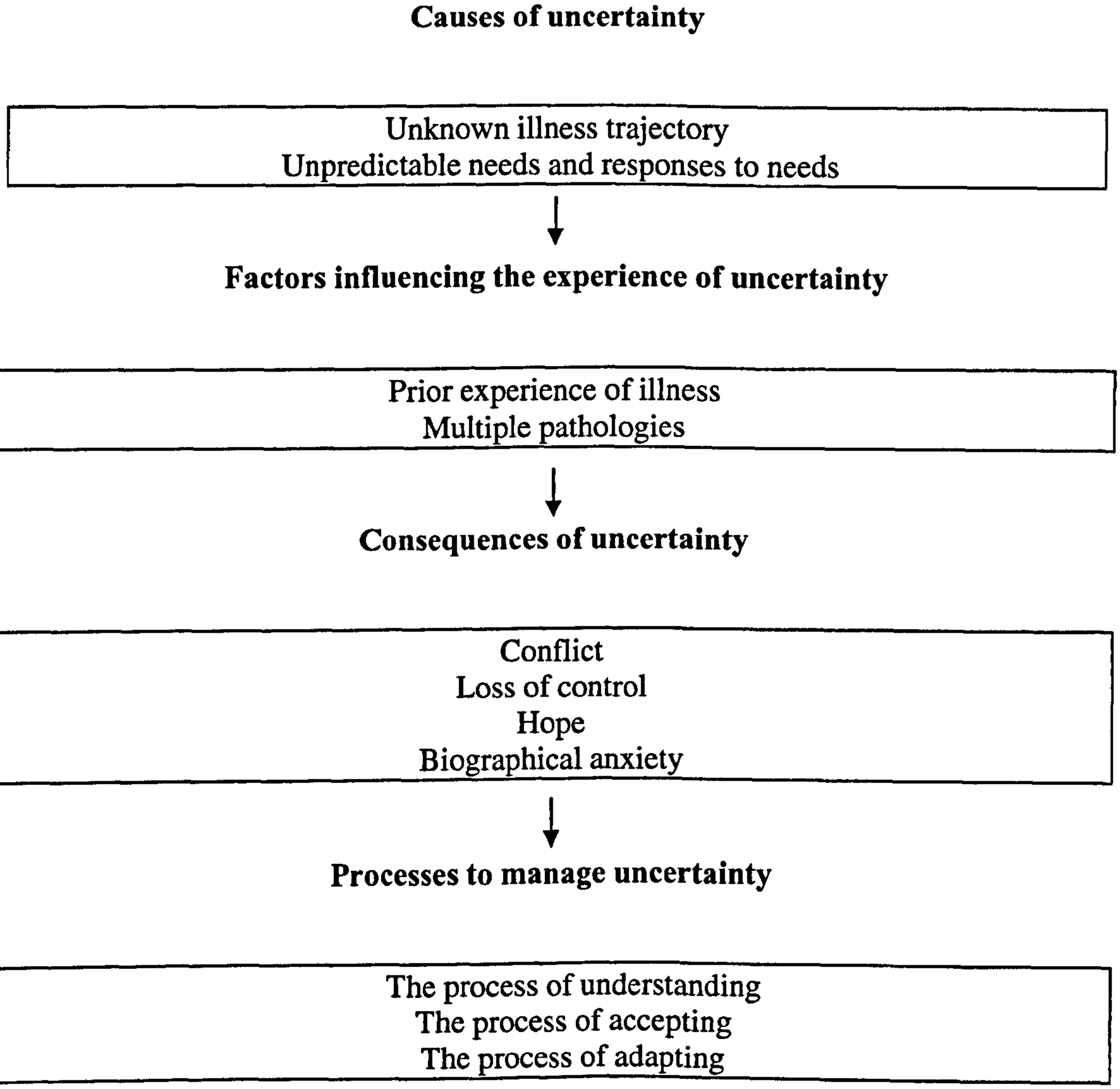
The following chapter identifies the causes, influencing factors, and consequences of uncertainty across the illness trajectory, as shown in figure 8. This is followed in chapter 8 by a description of the processes by which mastery over fluctuating uncertainty over the course of the illness trajectory was gained (the

process of understanding), the process of managing constant, background uncertainty (the process of accepting), and how professional staff work with chronically ill people and their families within an uncertain context (the process of adapting). Chapter 9 then gives a description of the strategies used to adapt to uncertainty at the interface between chronically ill people, their carers and professional staff. These strategies were maintaining continuity of chosen carer, and maintaining mutual exchange.

This study was designed to allow comparisons to be made between participants in different settings in order that commonalities and differences between experiences might illuminate the exploration of chronic illness. With this in mind, the following chapters present quotes from both the hospital and special school setting in order to demonstrate areas of commonality and to explore areas in which differences emerge.

This chapter outlines the dimensions, influencing factors and consequences of uncertainty in order to place the analysis of the processes used to manage uncertainty in its full experiential context.

Figure 8: **Dimensions of uncertainty across the illness trajectory**



Causes of uncertainty

Unknown illness trajectory Unpredictable needs and responses to needs

1. Unknown illness trajectory

This section outlines the ways in which heightened uncertainty was experienced at each of four stages of the illness trajectory, namely at pre-diagnosis, peri-diagnosis, care transition, and prognostic predictions about life-expectancy. Uncertainty was inextricably linked with the stages of the illness trajectory and had a time dimension to it in that uncertainty would increase and then decrease when a new stage in the trajectory was reached and managed. This is referred to as the ebb and flow of uncertainty and is presented here in relation to the stages of the illness trajectory. The illness trajectory experienced by participants is conceptualised as beginning at pre-diagnosis with the onset of symptoms and ending only with death. In this study, participants expressed uncertainty in relation to the *"Unknown-ness of it all"* (Catherine's husband, interview one, hospital). By this, participants were referring to firstly the lack of familiarity with their illness and its cause, diagnosis and prognosis, and secondly, the perceived lack of experiential knowledge of the way in which the illness trajectory would unfold. Lack of familiarity and experiential knowledge led to uncertainty about the way the illness trajectory would manifest itself and would affect the person and family.

a) Pre-diagnosis

For the patients, children, carers and parents in the study, the chronic illness journey began with an unfamiliar, unpredictable group of pre-diagnostic symptoms, the cause or necessary response to which was unclear and uncertain. In phase one, without exception, participants referred to T.I.A.s (Transient Ischaemic Attacks) that the patient had experienced before they had a major stroke. These attacks are caused by a temporary lack of oxygen to the brain which results in temporary symptoms similar to those of a stroke. Around 5% of people suffer from one or more T.I.A.s before experiencing a major stroke (Dennis & Warlow, 1987) and these unpredictable attacks are now recognised as early warnings of a stroke. All of the interviewees talked about these attacks as a collection of symptoms and decreases in physical abilities, the occurrence, severity, and cause of which could not be predicted. During these retrospective accounts, people told how they 'knew' something was wrong in both phases, but lacked the experiential or technical knowledge to deal effectively with symptoms.

"Well, he hadn't been well for about a week with these mini strokes. I knew something was going to happen, whether it was a heart attack or something but this is evidently what it has been." (Jim's wife, interview 1, phase 1)

*"I wasn't well, but I couldn't put my finger on it. I was keep saying "This hand's drooping". It was keep ... and to do your hair... I couldn't, and I mentioned it and they (*family members) *said "Why man, lass, it's dramatics". But I thought to myself it's too droopy and ... something's not right."* (Margaret, interview 1, phase 1)

Parents in phase two described a similar pre-diagnostic phase as one of uncertainty about both the cause and the appropriate response to a fluctuating set of physical

symptoms and needs. The place of the ill child within their family influenced the help seeking strategies used by families during the pre-diagnostic phase (appendix 10, table 14 shows the family structure of participants). Parents of only or eldest children were more uncertain since they had nothing to compare with and therefore if their gut feeling of something wrong was disregarded, they were more likely to believe the formal carer. Parents of children who had older siblings were more likely to insist that there was something wrong with their child in the peri-diagnostic phase.

"Why, I knew there was something wrong a long time before he started school. He's the eldest so you don't have much to go on ... just a feeling and you can't make people listen cos' they think you're barmy." (Jake's father, interview 1, phase 2)

This frustration was also demonstrated in other diagnostic groups;

"From the moment she was born I watched and knew something wasn't right .. it didn't come out till she was about three that there was something wrong with her." (Rebecca's mother, interview 2, phase 2)

Awareness of symptoms led to overwhelming uncertainty about coping skills and about the future. This uncertainty was managed using a cyclical process of normalisation and de-normalisation of symptoms, which only ended when a diagnosis was reached. At first, participants attempted to normalise symptoms by attributing them to ordinary colds or tiredness attributed to working too hard.

*"I said to my husband "I feel sort of tingly pins and needles in my arm" and it just went right through my arm and he thought that I was having him on. It went off so I thought it was all the extra work I'd taken on with **** being away from the office."*
(Catherine, interview 1, phase 1)

"My Mam kept worrying about me cough. But I wasn't. It was just like... colds and stuff. It wasn't now't really."
(Monica, interview 1, phase2)

Participants reached a stage where normalisation was no longer possible due to the need for information and practical help to address the uncertainty surrounding a possible diagnosis. For every patient and child in this study, the process that preceded hospital admission involved recognition by families that they could no longer cope with the uncertainty about cause and prognosis and a decision made by the family to request hospital admission in order to gain medical and therapeutic assistance for the patient.

In most cases, contact with formal care did not immediately result in hospital admission, leaving participants with increased uncertainty about how to deal with symptoms of which they understood little. This uncertainty seemed to destabilise attempts at normalisation; participants dealt with the uncertainty of cause and response to symptoms by de-normalising their situation and strongly asserting that something was terribly wrong.

"Teaching him to ride a bike was terrible because I mean he used to fall. He used to peddle and then go whack, right over. We pushed him because we didn't know what was wrong with him ... we just knew there was something wrong but ... I mean, we were just getting called over anxious parents, you know, that was doing my head in because I thought, you know, they're just not listening" (Peter's mother, interview 1, phase 2)

The fact that requests for help and information were perceived to be down-played by professional staff led again to heightened uncertainty that was managed by renormalising their response to symptoms and incorporating them into their daily lives.

"I've never felt ill, this is what's got me, I've never felt ill. Dr S. came and said it was nothing to worry about. After that I felt a little bit ... sickly, sort o' style, not, nothing

to be ... you know, just potter about to get a bit fresh air." (Susan, interview 1, phase 1)

"I pushed so much to find out that there was something wrong with her and I realised that I probably had a lot more pushing to do. I thought I was better working forwards than backwards and getting on with things for the sake of my husband." (Rebecca's mother, interview 1, phase 2)

In only one exception to this, the illness (spina bifida) was visible from birth and the parents were told soon after birth that their child would be physically impaired. Even in this case, there was a delay of several days before staff confirmed diagnosis; during this the parents went through a stage of uncertainty about the unknown and unpredictable way their baby was being looked after in contrast with other babies on the ward.

In phase one, following the major stroke, the longest any of the patients waited for admission to hospital was three days and in that period it became clear that the families could or would not cope with the overwhelming uncertainty about the origin of symptoms and what the appropriate response to those symptoms should be, thus precipitating admission to hospital. This final de-normalisation of symptoms, that could no longer be managed within the daily lives of participants, resulted in further requests for help.

"The Doctor came about 6 O'clock and he said it might pass off. He came back at 10 and he was just the same. He said wait for the doctor to come in the morning. Well, I wasn't even prepared ... and I couldn't hold him. I was going down and down and down and I just couldn't ... so two days later the doctor pops in and I says 'Look Doctor, I'm not superwoman ... something's got to give.' So then the Doctor came and got him in here (Hospital)". (Joseph's wife, interview 1, phase 1)

This was followed by a growing awareness of a likely diagnosis coupled with a realisation that normalisation of symptoms was impossible.

"They must have gotten me to bed Friday night and couldn't get me up again. They knew they couldn't manage after that so we got the doctor out Friday night. He came about six, examined me and he wasn't quite sure whether it was a stroke or not so off he popped. No tablets or nothing and of course the joke was that we all knew it was a stroke." (Thomas, interview 1, phase 1)

In phase one, each of the family carers and some of the patients (n=6), asserted that they realised what the diagnosis would be before this was confirmed by medical staff. In phase two, although only three of the parents made this assertion, they all shared a desire for certainty and clarity about medical, practical and financial help for the patient or child.

"I mean generally, for example, I needed to give up work and yet we still didn't know what exactly was wrong. It made getting benefits very difficult and then deciding which school was best for Toby was very difficult."
(Toby's mother, interview 1, phase 1)

Although the time length between help seeking and diagnosis was often much longer in phase two compared to phase one, a similar pattern of uncertainty about symptom management that was responded to by a cyclical process of normalising and de-normalising symptoms.

"She was finding it hard in mainstream school, yeah, cos she was out of breath, she couldn't do P.E. and I didn't feel that the input was good for her because she wasn't being cared for properly .... and I mean she was off a lot and they thought she was just truanting. So I pushed and pushed and pushed, I said if you don't find out what's wrong with the bairn, I'll take her out (of school) *altogether. So, eventually they said, yeah it's cystic fibrosis and maybe we should think of moving her from there and putting her into another school."* (Monica's mother, interview 2, phase2)

This struggle for certainty and clarity of information and support, against a background of overwhelming uncertainty, set the tone for the subsequent illness

journey that was characterised by an ebb and flow of uncertainty about the cause, diagnosis, treatment, and future course of the illness and the interface between families and professional carers.

b) Diagnosis

In every case for both adults and children, the diagnostic process began with a stay in hospital characterised by a battery of tests to determine the nature of the diagnosis. The fact that participants could not predict, or understand the meaning of these tests contributed to the increased uncertainty at this stage.

"He had an X-ray last night and ... whether they're still examining it or not I don't know but they're not too happy with the way he's swallowing. But it seems like they won't tell us anything ... they won't tell us what it is, what's caused this and if they won't tell us that, they can't even give us a clue about what they're looking for and why all the tests. Poor Mat feels like a guinea pig in a cage". (Matthew's wife, interview 1, phase 1)

Observation data taken from the hospital phase of the study showed that patients were admitted to hospital and did not receive any therapy for their condition until several tests were carried out and a clinical diagnosis of their symptoms was made. Similarly, the children were also exposed to tests that involved lengthy periods in hospital, without apparently receiving therapeutic intervention. While this increased uncertainty about the cause and diagnosis of the illness, it also created uncertainty about the most appropriate way of meeting the needs of the ill child or adult. The tension between the professional need to make a diagnosis, against a perceived need for therapy to commence immediately, created an apparent background of conflict between families and professional groups of staff.

"Being in hospital .... the tests were a nightmare. We knew he was brain damaged and in them days you just accepted there was nothing could be done so why all the tests? In the end I says 'Look I can look after him myself, I don't need advice or meddling from you'. I think if they'd put one more needle in him I would have done a murder, so I took him home and waited for an out-patient appointment to get the results." (Billy's mother, interview 2, phase 2)

The peri-diagnostic period was therefore often characterised by conflict with service providers, and unpredictability over symptoms, their causes, and their future consequences.

Questionnaire data indicates that for respondents from all professional groups, their main immediate aim of care would be to gather information about functional, social and physical aspects of symptoms and needs so that an accurate diagnosis, and subsequent care plan could be reached. For example, immediate aims were identified as;

"To establish his level of competency of swallowing" (Speech therapist 2, questionnaire, phase 1)

"To gather more comprehensive info on Simon's cognitive/communication, his behaviour at school, physical needs, medical needs, social context – with friends at school, home." (Teacher 1, questionnaire, phase 2)

These information gathering exercises, while entirely necessary for the physical well-being of the ill person, were seen to be at odds with the expressed need of families to receive, rather than give, information and therapy. Families found the peri-diagnostic period a frustrating and stressful time that did little to address the information and support needs that were important to them.

"They took her down for an X-ray ... not an ... a brain scan ... and she got all upset and I thought, what a waste of time and money cos' everyone knew it was a stroke. So they were doing all that but they were missing the little things that I was doing at home ... like it wouldn't occur to them to put her make-up on or ... she's wet and I

would have liked tests on that to see if that would be forever ... but they have different ideas I suppose and they haven't got a lot of time." (Anne's daughter, interview 1, phase 1)

During the peri-diagnostic period, families and patients also expressed frustration that the emphasis on bio-physical aspects did little to address the person behind the illness in relation to the beliefs they held about their illness and its prognosis or how they and their families coped with the symptoms.

*"I'm having a tummy scan this afternoon but I have to have a head scan to see whether the bleeding caused it (*the stroke) *or just a clot. You know, whether it was a cerebral haemorrhage or just a thrombosis."*
H. That's interesting. You know all the right terms.
"It's the second time it's happened. I've read all about it. That's why it's such a joke ... being here. I know what's wrong with me, I know how to look after myself ... I've got a home help actually ... but all these tests and ... 'you can't go home yet, Peggy'. If there was anything they could do or say different from the last ... but there won't be". (Sally, interview 1, phase 1)

Once a diagnosis of the illness was reached, this information conferred some certainty over the origins of the puzzling pre-diagnostic symptoms and allowed participants to enter a path of service provision. The ebb and flow of uncertainty therefore reduced in that confirmation of diagnosis was seen as important for two main reasons; firstly it affirmed and legitimised intuition and tacit knowledge about symptoms, and secondly, it was seen to be essential for access to professional service provision to gain assistance, therapy and a level of control for the child and his/her family. The feeling that, at last, needs would be fully addressed, reduced feelings of uncertainty, and allowed predictions and plans to be made about the future illness management.

*"It wasn't that I wanted some one to say 'Yes, you're right about Becky'. It was more that I knew she wouldn't cope in mainstream school. But if they won't say there's something wrong, you can't get them into special schools, can you?. So as I say, I had this Health Visitor and it was her that picked it up. You know, she took what I said and persevered a long time with it and she was the one that got her a nursery place at *** (*Special Needs Nursery)." (Rebecca's mother, interview 1, phase 2)

Despite assertions that participants had already realised what the likely diagnosis would be, the process of receiving a medical diagnosis created shock, grief and a sense of loss of the imagined 'normal' child or of the previously able-bodied adult. In particular, disappointment was expressed that a diagnosis did not lead to certainty about the predictability of future symptoms and impairments, or whether and to what extent the perceived loss would be permanent or temporary.

"Yes, ... 7. It'll be 8 weeks coming up on Monday since the stroke. I try to get to know from the staff how long he's going to be in but I know they can't really ever tell you with a stroke, it's all 'sometimes they recover quickly', but I believe he's had a pretty bad one ... so ... I take it that it's going to be a while ... but I can't, no-one will say "Oh, it's going to be 3 months, 6 months", it just depends". (Matthew's wife, interview 1, phase 1)

"You try and wonder what's ahead of you and people try and reassure you but you know for a fact that no reassurance is possible because you don't know how bad it's hit you" (Sally, observation period 2, phase 1)

The immediate post-diagnosis period was characterised by unfamiliarity of illness and inability to predict the immediate and long-term future in terms of information and knowledge about the possible cause, physical prognosis of the illness, the health service intervention that would be required, and the future effects on the social and emotional worlds of participants.

c) Care transitions

The heightened level of uncertainty about prognosis provided the background for decisions that were required regarding the future of the chronically ill person. Following diagnosis of a disabling condition, patients and children were channelled into service provision according to a) demands made by the family, b) assessment and prioritisation of need made by service providers, and c) local provision to meet those demands and needs. In situations where all three factors closely matched, this led to a therapeutic relationship characterised by certainty about provision of services. More often, however, either local provision, or assessment of needs did not meet the expectations of the family, causing uncertainty about needs and responses to needs. In phase two, three of the children had been in the special education system from nursery school onwards and, for them and their parents, the process of acknowledging the chronic illness and accessing appropriate service provision was described as relatively straightforward and free from uncertainty about the ways needs would be met.

*"He's been at Smithson for nearly 4 years now. In the nursery, then reception, then with Mrs ******* for two years. It's been very good. I was very impressed and I took my husband on a visit and we were very impressed and they prepared Toby's statement while we were waiting and decided that the best place was right there at the school."* (Toby's mother, interview 1, phase 2*)*

For the remaining children, however, a move from mainstream to special education represented a more traumatic change in their lives and in the lives of their families, characterised by uncertainty over how best to meet the needs of their child. This uncertainty was expressed in relation to whether decisions about special

education were made at the right time and the consequences the decision would have on the future of the child.

"Really we kept him in mainstream too long. His work suffered. We thought it would do him good stopping in main stream school till he was 11 because he was with all his friends but really he should have been in Smithson before because his work went right back. Just through not being able to walk and being fussed over." (Peter's father, interview 1, phase 2)

Regardless of who initiated the move, this period was characterised by uncertainty over decisions that would affect the rest of their child's lives.

"She was finding it hard in mainstream school. She wasn't being cared for properly, you know what I mean? Not in a neglectful way but it was such a lot for them to cope with. But she's a very, very bright girl, you know, and I says you know how far would special school take her with her being so intelligent?" (Monica's mother, interview 2, phase 2)

Acceptance of the need for special education represented acceptance both of the loss of the idea of a 'normal' child and a move towards acceptance of the chronicity inherent within the illness.

As in phase two, participants in phase one saw the period following diagnosis as one marked by uncertainty over assessment of need and who or where to best meet those needs. For example, Anne's daughter was worried that her mum would be discharged into her care but was having difficulty verbalising these fears in case of a) judgemental attitudes from staff who might assume a daughter would wish to care for her mother, b) pressure from her brother who, in tune with the prevailing local culture, felt that she had a moral obligation to take her mother home, and c) fear of stigma and lack of understanding if she disclosed that she has epilepsy and for this reason felt unable to cope with her mum's needs.

Plus, like as I say, I'm an epileptic, you know, and so Mam lives on her own and I'm thinking to myself... well how am I going to cope if Mam's got to come home and it's a twenty four hour job, which I know I couldn't cope with, you know, and I think these things go through your mind". (Anne's daughter, interview 2, phase 1)

The majority of patients (n=8) were assessed as needing home care following discharge from hospital. Again, this process was characterised by uncertainty about how best to meet the needs of the stroke survivor.

"*Oh, I want her home. That's one of the things the nurses asked me to ... well... two or three weeks ago, they said 'Do you want **** to go into a nursing home or do you want her home?' I said 'oh, I want her home.' I said she wants to come home as well, you know. I said I don't want her in a nursing home. I've looked after her for the last two years. Provided I get help, you know, with toilet facilities and that sort of thing ... bath nurse and I'll arrange for a home help. I'll hire someone in ... or I might get one from social services, I don't know, but I will find out.*" (Ina's husband, interview 2, phase 1)

In four cases, the patient was deemed too physically disabled to go home and plans were made to place them in a nursing home (see appendix 10, table 6). All but one remained aphasic and were therefore unable to be interviewed about this. The remaining patient was too distressed during his interview to discuss this matter. However, one lady told me about her reluctance to accept adaptations to her home. This appeared to correlate with a denial of the temporal aspect of her illness and its physical effects and a desire to create certainty about her prognosis.

"*I think I would prefer to go for the full recovery and do it that way rather than get the car adapted and then, you know, manage like that and I think it might delay getting back to normal, using that word again. I feel that if I get adaptations I would be accepting second best and it is my aim not to accept anything less than ... all I can do.*" (Catherine, interview 2, phase 1)

For participants, therefore, this period of the illness trajectory was characterised by major change that was influenced by unpredictability over service providers and uncertainty about the accommodations that were necessary in light of the physical impairment brought on by the illness.

d) Future prognosis

In each phase, there were those who had been given a diagnosis of a terminal or life-limiting illness (such as a brain tumour, or Duchenne Muscular Dystrophy), and those who had less easily definable but still life-threatening illnesses such as asthma and diabetes. There appeared to be no difference for each of these groups in terms of their lived experiences of uncertainty and perceived lack of certainty or predictability over the illness trajectory. Although the illness trajectory in this study was not seen to end in death for any of the participants, fear and anxiety about the unpredictability of the duration and severity of symptoms and their consequences was a common theme expressed by participants in each phase. In the hospital phase, patients wished for a full recovery and rehabilitation aims were often discussed in terms of recovery and cure. However, the majority of patients were left with considerable health needs and physical disabilities one year after the stroke (as shown in appendix 10, table 10). Participants began to view cure or recovery as an increasingly unobtainable goal and would discuss the future in terms of fear and uncertainty. Fears for the future involved an acknowledgement of the possibility of dying as a result of the chronic illness. There was evidence of uncertainty about the prognostic outcome, the ways in

which participants could expect to be guided through this process, and the coping strategies that would be necessary.

"I'm not sure how things are going to affect my future. You look on the black side you know."(Susan, interview 2, phase 1)

Seeing death and dying was a part of the every-day experience for both the children and the adults in this study and it was usually discussed in an abstract way that did not relate to the person themselves. For example, in phase one, the patients often commented on periods in which someone died on the ward. They reported feelings of sadness and sympathy for relatives of the person but were unwilling or unable to relate this discussion with their own fears about death.

For example,

"It is depressing I think, being with older people for extended periods. It was just, you know, the thought of all these sick people, old dying people. I mean ... I was sick as well, but you were sort of stuck in there and I just felt it was depressing." (Catherine, interview 3, phase 1)

Other patients, however, were able to face the fear of death more openly and expressed frustration that the organisational context did not seem able to take this acceptance into account.

"I'm 85, so I've got to die sometime. It's not whether I'm going to die, it's where I'm going to die. What I mean is, I don't care if I don't get any better." (Thomas, interview 3, phase 1)

In phase two, written documentation showed that the death of a child from the special school occurred approximately once a year and was almost always preceded by a lengthy absence from school. Children were encouraged to speak to their form

tutor if they had worries or were upset by the death of a friend and the child was occasionally mentioned in class to give the group an opportunity to remember the child in a supportive atmosphere. The following observation memo illustrates this:

Observation period 16. Class 1.G
The teacher based a geography lesson around a class trip that was taken to a farm one year previously. He began by asking the class general questions about the animals and the formation of the fields when a child said, "Oliver liked the pigs. He said they were smelly." Everyone laughed and the teacher commented that it was nice to remember how funny and friendly Oliver was. He explained that Oliver had died of a weak heart and his illness was not contagious. He invited questions and none came. The class continued to reminisce about Oliver's sense of humour for several moments until the teacher brought the lesson back to its original focus. Following the lesson, the teacher told me that the school takes the issue of death and dying very seriously and give pastoral help where necessary. He felt it was important to dispel myths about illnesses such as whether it was contagious as children often imagine incorrect and disturbing things about what they see and then relate these things to their own illnesses.

Although dying and death can be conceptualised as an inevitable part of the illness trajectory, none of the participants in phase two engaged in direct discussions about this issue in relation to their own child. It is possible to suggest that acknowledgement of the likelihood of the death of a child was too painful to discuss with a comparative stranger.

"Monica's friend ... she was only 12 but she died. It's such a shame. I don't think people should talk about that. Monica's my bairn and it's hard to think about it."
(Monica's mother, interview 1, phase 2)

Desire for certainty of information about prognosis was often expressed in relation to hopes for a cure for the life-limiting condition.

"The Muscular Dystrophy family officer or whatever you call it. Her in the social services has a lot to do with it and she tells you about fundraising to help find a cure. That's our great hope." (Jake's father, interview 1, phase 2)

An interesting aspect of the school experience for children was the apparent lack of conflict between students and staff seen during observation. Children were rarely observed in direct confrontation with teachers or other members of staff. This may have been a function of my presence (a discussion of this 'Hawthorne effect' is made elsewhere in this thesis). However, it is also possible to suggest that this 'soft' approach to discipline taken by staff was a function of low expectations of children with serious physical impairments and uncertain life expectancy. Informal discussions with staff revealed that they felt a duty of care to the children's emotional and psychological well-being within the context of terminal or life-limiting illness which over-rode their educational commitment. This involved creating a stable environment characterised by certainty over responses to need. A teacher told me;

"When I've got a child who isn't going to see their 18th birthday, I'm not going to shout and scream if they haven't done their homework. I'm not even going to shout at their best-friend, because why upset things when they've got a life threatening illness?" (Teacher 7, observation period 16, phase 2)

Summary of illness trajectory

It seems that for the participants in this study, the illness trajectory was characterised by unpredictability and lack of certainty over both process (diagnosis, acute episodes and unstable needs) and outcome (the possibility of death at some point in the future). Aspects of this closely mirrors the chronic illness trajectory identified by

Corbin & Strauss (1992) in which the illness course is characterised by a time continuum from the pre-trajectory towards dying, interspersed by acute and unstable phases in between. However, as Woog (1992) points out, the trajectory can only be accurately be mapped and understood by service providers in retrospect. These findings indicate that the actual process of living through the trajectory is characterised by an inability to predict the way in which the trajectory will unfold with consequent fluctuations in the levels of uncertainty at each stage of the trajectory. Most importantly, the trajectory was characterised by movement from overwhelming uncertainty about prognosis, towards a growing acceptance of the prognostic limits of medical information. Additionally to the ebb and flow of uncertainty, participants expressed a continuous background level of uncertainty rooted in an inability to predict or control the consequences of needs on the ill person and the family, and the ways and environments in which these needs might be met.

Although the organisational, social and familial contexts of the participants in each phase were qualitatively different, these differences did not seem to influence the experience of unpredictability of the bodily aspects of chronic illnesses, or the unpredictability and lack of control over the ways and contexts in which these needs were met. These needs and contexts are discussed in the following section that elucidates the unpredictable nature of needs and the unpredictability of the physical, social and organisational worlds encountered by the ill person and family.

2. Unpredictable needs and responses to needs

This section illustrates the peaks and troughs of the illness trajectory as the acute deteriorations in physical health whose occurrence and severity were impossible to predict. Inability to predict these occurrences led to heightened uncertainty and these factors made it difficult to predict or interpret progress in relation to present and future impairment. It then describes the contextual location of bodily needs as experienced by participants in this study during the illness trajectory: firstly, the social environment that was the participant's social world; secondly, the organisational environment in which medical or educational needs were addressed; and thirdly, the physical environment that included pavements and inaccessible toilets.

a) Peaks and troughs

Following diagnosis, almost all participants reported acute incidences of ill health that precipitated re-admission to hospital. Participants reported feelings of loss of certainty during these episodes over physical deterioration that they were powerless to prevent:

"The neurologist felt that my blood pressure was too high for someone of my age and ... that perhaps needed some investigation. Anyway, it fluctuates occasionally so I just drop and then you don't know if you've had another stroke and it's awful because you have to go back in to the ward and face the possibility of not being able to walk again and again. It's very depressing." (Catherine, interview 3, phase 1)

A key difference between each phase was the time from diagnosis to the collection of data about these processes. In particular, stroke patients were included in the study as little as 24 hours following diagnosis, whereas children had often received a

diagnosis many years prior to the study. Data from each phase were compared to ascertain whether the time difference from diagnosis to data collection led to commonalities and differences in representations of experiences of the illness trajectory. Following diagnosis of a childhood illness, the experience of living with the illness for some considerable time did little to confer a feeling of certainty or predictability over the acute episodes of ill health and unstable fluctuations of needs that were overriding characteristics of the illnesses under study. People in both phases expressed this unpredictability in terms of the biophysical aspects of the disease process, over which they felt no control:

" Well I have to have an operation on the heart to have a new valve put in. I'm all ... I've got the things on me for my chest and my heart. Every time I move it goes off. They'll be taking it off soon. You never know when the angina will come on. It's .. I get frightened." (Margaret, interview 1, phase 1)

"*We're not quite sure what will hit us next ...it could be the whole body radiotherapy he had before the ... to knock out ... the bone marrow had to be destroyed first and then the new put in so it ...so it's been infection after infection. Oh Toby, what will it be next?"*
(Toby's mother, interview 1, phase 2)

The unpredictability over the occurrence and severity of symptoms continued to have a negative impact on the lives of families in similar ways in each setting. This was particularly the case when the person suffered more than one diagnosis of chronic illness, creating multiple health needs. The subsequent fluctuations in health prevented participants from planning too far into the future for social and family events, work, school events and holidays. For example,

"Just when I hurt my back. When I've got a really bad pain ... I don't know if I can go to London to see ... my Dad. I hurt my foot on holiday. When I got off the sunbed I

went over like that. My Dad had to put an elastoplast on it and he said we had to come home early. It was a right pig." (Rebecca, interview 2, phase 1)

"We never know what he'll be like. If he'll be well enough to do what we have planned. It's rotten for his little sister when we have to cancel. But that's life." *(*Sam's father, interview 1, phase 2*)*

In phase one, most of the participants were forthright about the physical needs of the chronically ill person and the impact it had on their lives. A common problem among the stroke patients was incontinence, both urinary and faecal, which by its very nature cannot be predicted or controlled. The subsequent effect on emotional and social well-being was often quite profound and heart-felt:

*"Now, the catheter ... one day last week he had ... he didn't know me and was saying "Please take me to the toilet, please help me". I said "I can't, you've got a bag there, you're alright" and he sort of settled for a little while and then he said something and I said "I'm your Margaret, I'm your wife". He said "Well, if you're my wife, please take me to the toilet". He says "I want a bit of dignity". He said "I'm not used to being dirty". He thinks he's wetting the place. He says "All these wet beds. All these wet chairs. I want my dignity. I don't want to dirty". (*Joseph's wife, interview 1, phase 1*)*

Children themselves were unwilling to talk about these physical problems, a fact that was respected within the parameters of this research that viewed children as active participants with the ability to withdraw consent at any time. It is possible to suggest that rather than being embarrassed about bodily functions, children felt an element of control over their bodies as a result of the dignified, private way in which their needs were addressed within the school and were therefore able to refuse to share information about this issue. During an interview with Lucy, she told me,

"I'll have to go now. The nurse has to do my catheter."
H: Oh, okay, what does she do?
"It's private. None of your business. It's private, right? Do you want a sweet?" (Lucy, interview 2, phase 2)

In contrast, the socialisation of patients in terms of lack of privacy and access to bodies is well documented (Lawler, 1991). It is possible to suggest that patients discussed this issue all too readily because they were so familiar with sharing personal, private information about bodily functions. Regardless of the ways in which these needs were described, the experiences of these fluctuating, unpredictable needs prevented participants from interpreting their progress in terms of improvement or movement towards cure:

"If you know it's going to be another 3 weeks, a month or whatever, you know that you've got that to face and you've got to work at it but if you don't then you're working blind, aren't you?" (Thomas, interview 3, phase 1)

It seemed that the unpredictability of these needs did not diminish over time, with participants in the school setting being equally likely to express these difficulties as those in the hospital setting. The temporal element of changing needs was evident in discussions with participants concerning what the future held for them in relation to their illnesses. This feeling of lack of certainty about the disease process was evident regardless of proximity to diagnosis.

"I think the thing is ... you know just being left sort of, you're not in the dark, but you are in a way, you know. I mean like they say well the brain cells in the front has gone, which we know ... is that ... but then they don't turn round and say well she'll still function for this and that and the other so therefore you are left in the dark that way." (Anne's daughter, interview 2, phase 1)

In addition to the unpredictability and lack of control over the physical nature of fluctuating needs, participants in both phases came to a realisation that this was strongly linked to the social and physical context of participants' worlds. This is the subject of the following section.

A) Social world

The unpredictability and uncontrollability of fluctuating needs was influenced by the social world of participants in that they were unsure of the reaction their needs would elicit from people unfamiliar with illness. In particular, they were unable to predict with any certainty the ways in which their needs and impairments would be met by friends, family and outsiders.

*'I do feel a little bit self-conscious and you can sense people ... aren't being nosey or anything like that but they just automatically turn ... I sometimes feel going out of a restaurant people might think I'm drunk.' (*Catherine, interview 3, phase 1*)*

Describing her disabled son's reaction to his father's stroke, Joseph's wife told me;

*"He's very upset about it all, you know. I mean he can't understand. I said to him " Dad's not coming home for a while, he's in hospital" and he just listened ... and there was another time he asked where Dad was and I said " He's had a stroke". "Don't say that, don't, don't!!" he shouted. He's never mentioned it since but ... I mean he is upset". (*Joseph's wife, interview 1, phase 1*)*

In phase two, children sometimes alluded to the negative reactions they faced to their physical impairments.

*"One of the problems I find is ... people abusing ... they don't know your situation, they don't know what you're capable of. Well, they mainly think you can't do anything because you're sitting in a wheelchair so ... when they abuse I ignore it." (*Hanif, interview 1, phase 2*)*

*"Because she started playing outside but the kids tended to think she was a toy in a wheelchair. It was last summer holidays and she ended up going over the kerb in her wheelchair .. and after that, she wouldn't go out." (*Lucy's mother, interview 2, phase 2*)*

The children often had difficulty in predicting and maintaining control over membership of their social world. This contributed to feelings of uncertainty about their social environment. This occurred for several reasons, firstly, because of the

nature of special education, new pupils would often join the class from main-stream schools either mid way through term or at the start of each new term, thus joining the class at times other than the traditional September start of the school year. Secondly, the high hospital admission rate among children at the school, and sometimes the death of a child, caused unpredictable fluctuations in class membership in which children would often be away from school for weeks or even months at a time. Thirdly, as a result of the above factors, teachers often felt it necessary to move pupils to a new form in order to try to find a class where they would fit in better.

Observation and questionnaire data indicated that staff saw the facilitation of friendships and social activities as a priority in each phase, albeit in a structured 'therapeutic' manner (the provision of day centres and sitting services, for example). However, most of the children had difficulty in identifying a best friend and most participants expressed increased loneliness and social isolation following the onset of illness. It is possible to align this finding with the assertion of the disability movement of the inability of Western society to accommodate chronic need in a way that allows for personhood and friendships to flourish. In most cases, all but the closest of friends and family found it impossible to become involved in the fluctuating needs of the ill person and the social network was described as being very small for the vast majority of participants. This is exemplified in data from parents who expressed concern over the unpredictability of needs of other children with chronic illnesses. Parents felt unable to allow a friend from the special school to stay at their house because they doubted their ability to cope with the unpredictable needs of another child even for a few short hours. This had the result that, particularly

during the summer break, the children themselves had no contact at all with their school friends. Even during the school term, a visit may have necessitated an over-night stay as a result of the school's huge catchment area, and was therefore prohibited.

> *"In the school holidays, I do think she misses out a bit because her friends live so far away. She would love Sarah to come and stay but she's got asthma. Her lips are blue and ... well, we've got enough here with Lucy. It's ... it would be too much I think."* (Lucy's mother, interview 2, phase 2)

> *"I'm always worried in case Nicola takes poorly because I would hate anything to happen, you know. Isabel wants her to sleep and things like that and I don't want to take the responsibility."* (Isabel's mother, interview 1, phase 2)

It is possible to suggest that a growing fear of litigation, a sense of individual burden, alongside the breakdown of the extended family created the context for these findings to flourish. The reasons why parents perhaps failed to value or have confidence in their own caring skills in order to use them with another child are complex and not easily explicated here. However, it may be that it points to the difficulty faced by professional staff in developing confidence and a sense of transferability of skills to patients and their families, while at the same time making them feel supported and not simply abandoned to 'get on with it'.

B) Organisational world

Within the organisational context, participants were often unable to predict which carers they would have contact with and what the aims of care would be. This maintained a background level of uncertainty across the trajectory. The comments regarding this generally focused on the lack of continuity of staff.

*"So, you know, that was ... I went thinking I would see Dr*** and he would see the progress I'd made and all the rest of it, where-as I was assessed by some-one who didn't know what I was like in the beginning. I mean I know the notes were there but it's not the same."* (Catherine, interview 3, phase 1)

Parents often expressed uncertainty about whether unfamiliar and untrained service providers would be able to meet the complex, unique needs of their child.

"*He's not toilet trained and he's got ever such dry skin at the moment, haven't you? His skin has been driving him crackers. We've been smearing him in cream but it's very dry. It could be the whole body radiotherapy he had before the ... to knock out ... the bone marrow had to be destroyed first and then the new put in so it ... I didn't think the school would cope with the toileting and the cream and so I think it's best for him to stay home, apart from the risk of infection."* (Toby's mother, interview 1, phase 2)

"His teacher said 'how would you feel about letting Billy out on his own?' To let him go to resi (residential school unit)*, like. I said to her, you've upset me now. Because you read these stories and you see these programmes on the telly about these places and you know, you think they're okay and ... then they're not and ..."* (Billy's mother, interview 1, phase 2)

It seems that unpredictability and inability to successfully navigate the system for organisation and management of care created uncertainty for participants who were unable to assess what their needs would be in the future or how and by whom those needs would be met. This added to the difficulty in planning ahead to accommodate the needs of the ill person and family members. It also contributed to conflict between families and staff concerning decisions about care and future management of care. This is evidenced in the following quote from a carer who felt angry that decisions were being made by staff who had not been involved from the start of the illness;

"I had a home-help and cross-roads girls coming in at night and they put him to bed and in the morning the home help got him up and we have a stair lift so they put him on the stair lift and brought him down ... so he wasn't trapped upstairs. But now,

they told me the first night that I wouldn't be able to manage him in the house. I know I'm 80 but we managed before ... he's diabetic and his legs have been dreadful and he's falling at the least thing but the stroke didn't seem to make a lot of difference in that way. I know we could manage him again. But the social worker and the Doctor all say no." (Jim's wife, interview 2, phase 1)

Lack of continuity therefore appeared to hinder the therapeutic process by creating conflict and inability to plan for the future in both practical terms and in terms of understanding the future illness trajectory.

C) Physical world

Within the physical environment, participants reported frustration that they could not plan to go somewhere without first finding out if it was able to accommodate their physical needs. For instance, Peter's father reflected on a photograph taken by Peter during a family outing.

*"That was at ***** sea-front. There was a show for the bairns on so we went thinking that the disabled toilets would be there like always. We got there and they were shut, weren't they? And we knew we wouldn't manage him in the pub loo so he held on and held on until we got home. It puts us off going anywhere because he's such a private lad. He's devastated if he's wet."* (Peter's father, interview 1, phase 2)

This lack of accommodation added to the unpredictability and lack of control already experienced with regard to physical needs.

In both phases, an acceptance that the home environment required alteration to accommodate physical impairment represented an acceptance (or otherwise) of the loss of 'normality' caused by the chronic illness. This issue was one that people reflected on in phase one following discharge from hospital in relation to acceptance, or denial, of their own physical difference. Once home, they began to realise how

different their bodies were to their past selves. This was sometimes expressed in terms of unwillingness to accept adaptations to their houses or other aspects of their lives as this was seen as giving in to the disability. Conversely, some people viewed adapting the physical environment as a way of conferring some certainty and control over the illness process.

"He wants to be home. You see, this is the only thing we've got to hold on to. The hall, you know the passage way, there's the bathroom and the toilet there. There's no room to manoeuvre and there's that nasty bend on the stairs, it's no good for a stair lift and I'd said I would put a bed, you know, a single bed down and put it in anyway, so ... once I'd said that, they said he's ready for coming home." (Joseph's wife, interview 2, phase 1)

For the children in phase two, far from representing negative aspects of their disabilities, their aids and equipment seemed to signify a reclamation of certainty and predictability, and therefore control over their physical world. In some instances, electric wheelchairs were objects of desire for the children and the speed and controllability of a particular chair designated its owner a top place in the school hierarchy. Some of the boys used the metal footplates on their chairs as dangerous fighting tools with painful effects on whoever got in their way. Therefore, although these children were among the more seriously physically impaired children, the chairs conferred on them great strength and power among their peer groups. Unfortunately, both the unreliability of these machines, and the failings of the external environment meant that these advantages were uncertain and unpredictable outside of school grounds.

"I had a puncture in my other chair .. no this chair, about a week ago. I had to get one of the physios and use one of their stupid chairs. It was horrible because the seat

*was down here and ***** came flying at me and I couldn't get out of the way."*
*(*Simon, interview 1, phase 2*)*

It seems that participants in each phase were subject to contextual factors that influenced the ways in which their needs were met. These factors resulted in an illness course characterised by unpredictability, regardless of the type of diagnosis or medical management of that illness. An ability to understand aspects of the illness trajectory became increasingly important to participants in order to mediate their uncertainty and anxiety about the illness. The level of mastery achieved by participants was influenced by several factors that are discussed in the following section, namely, prior experience of illness, multiple pathologies, and time.

Factors influencing the experience of uncertainty within the chronic illness trajectory

Prior experience of illness Multiple pathologies

1. Prior experience of chronic illness

Prior experience of illness was seen in both phases to influence both technical, medical knowledge and tacit, experiential knowledge held by chronically ill people and their carers. In phase one, the majority of the stroke patients (n-7) and their carers (n-8) asserted that they had previous experience of seeing stroke in friends, neighbours, family members or in their own past medical history. This is unsurprising since stroke is one of the most common causes of impairment in Britain (Stroke Association, 2004). This past experience seemed to confer a certain level of knowledge about the acute episodes and needs alluded to earlier;

'Well, first of all my hand just went. I went to put my light on and of course I'd had a stroke before so I knew this was a mini stroke and I knew it might lead to the big one.' (Sally, interview 1, phase I)

Others had more general experience of caring for people with chronic illness. One lady worked as a home carer and had a great deal of experience in dealing with impairment and multiple needs. She asserted that she knew the diagnosis long before it was confirmed by medical staff;

"Well, I work with old people actually ... not that I've experienced anyone having a stroke but you do sort of pick things up, yes. I mean I did know straight away what it was... that he was leading up for a stroke and I mean the Doctors can't stop them happening I think ... so we just sat on it and waited. We managed." (Matthew's wife, interview 1, phase1)

For some people, this technical or medical knowledge conferred a feeling of control over the pre-diagnostic phase and over predictions for the future. This mediated some of the uncertainty experienced during this period. One lady referred to the experience of caring for her mum, which allowed her to normalise the period and gave her the feeling that she had coping resources to deal with her husband's stroke;

"I've never worked since I had my son ... never been able to and I looked after my Dad when he was ill and then my Mam got dementia. She just used to live three doors up and that was hard. I used to have to go in on a night time and lock her in. The front door locks on the outside and I had to take the bolts off, me keep the keys and we used to have to go up at midnight sometimes and see that the gas fire and everything was off without her knowing these things, you know. So I mean I got the strength for all that, so surely the Lord will give me some for this". (Joseph's wife, interview 2, phase 1)

In phase two, aside from Billy's family, none of the parents had any previous experience of dealing with children with chronic illness, but had often suffered from chronic illnesses themselves prior to the diagnosis of their child. Those with experience of their own illnesses drew upon prior knowledge of the interface between families and service providers in order to negotiate the unpredictable illness trajectory;

"I'm on invalidity myself and income support, you know. I took my redundancy last year after the accident. I suppose it helped because like I say we've got the stuff that he needs and it's just keeping it going, you know? The staff forget if you don't remind them that you're here and I think I sussed that from before. If you want anything you have to push." (Jake's father, interview 1, phase 1)

It seems that prior experience conferred an ability to assimilate the illness trajectory within the person's own biography. In contrast, participants in both phases

who could identify no specific caring or illness experience reported a feeling of vulnerability due to their lack of technical and experiential knowledge;

"*Believe it or not, I've never been on a hospital ward. I've .. I was thinking to myself "What's that?" You know, is it for the blood pressure, the temperature, you know, is it that kind of thing, but I've never had time to ask the nurses ... which I will do because I think you've got to know these things. I think when you walk into a hospital you get such a fright when you see different things, you know.*" (Anne's daughter, interview 1, phase 1)

"*He's the eldest and he'd not been ill before, apart from colds and that. But we didn't have nothing to go on. He had a medical and we knew there was something wrong but we knew nowt about hospitals and that. It was frightening I don't mind admitting.*" (Jake's father, interview 1, phase 2)

Those people who could not identify prior experience of illness perceived this as a deficit that led to uncertainty and vulnerability to loss of control. In other words, they imagined that experiential knowledge of illness might have made their experience easier in some way;

*"I'd never even heard of it (*Cystic Fibrosis*) when our Monica was diagnosed. I've got 3 girls to my first marriage and I've got a little lady to my second marriage and none of them had ever been in hospital. It would have been easier, you know, if they had of been in a way 'cos then at least you would know what to expect."* (Monica's mother, interview 2, phase 2)

Participants who could identify no experiential knowledge seemed to have the most difficulty in grieving for the loss of normality engendered by the sudden onset of illness;

"My life had suddenly changed, you don't have time to ... adjust. You're literally changed drastically from one minute to the next. I know no-one with this and nothing about it and .. I just want to return to where we were and I suppose you can't write off this sort of experience but I want to forget about it, I want it behind me ... and just be normal.." (Catherine, interview 3, phase 1)

In order to explore the effects of prior experience at the interface between families and staff, the questionnaires included a scenario that involved prior or concurrent experience of chronic illness. Without exception, staff approached this issue in relation to carer burden and expressed concerns that the carer may not be able to cope with multiple demands caused by other caring responsibilities or their own illnesses. This would then precipitate offers of assistance that might include residential care for the chronically person. The potential positive effect of experiential knowledge on the levels of information and support needs was only addressed by one of the respondents, an occupational therapist, who commented,

> *"I would find out how they coped at home before coming into hospital."* (Occupational therapist 3, questionnaire, phase 1)

The emphasis on organisational and institutional responses to perceived carer burden therefore contrasted with the findings from patients, parents and carers. For them, prior experience of illness, parenting or caring conferred a level of experiential knowledge that allowed participants to normalise their experiences and minimise their uncertainty. However, lack of experience was seen to heighten the level of uncertainty experienced. Similarly to this, the incidence of multiple diagnoses of chronic illnesses was seen to increase the ability of participants to make sense of their journey in order to assimilate the effects of the illness into their lives. This is discussed in the following section.

2. Multiple pathology

As indicated in appendix 10 (tables 7,8, 15, and 16) all of the stroke patients bar one and 10 of the children suffered from two or more chronic illnesses that required medical intervention. These multiple diagnoses were usually interrelated in bio-physical terms, for example, several (n-6) stroke patients had a long history of hypertension which is recognised as a pre-cursor to stroke. In other cases, the diagnoses were mutually independent; for example, Toby suffered from a rare chromosomal disorder and was unlucky enough to develop leukaemia, independently from his original illness. In either case, the incidence of multiple pathology was seen to initially increase uncertainty and unpredictability concerning both immediate physical, psycho-social needs and possible needs in the future created by the new diagnosis;

"Well, I wasn't very good because I've got heart trouble as well, you see. A faulty heart valve so that didn't help. So when the first stroke happened I thought 'How am I going to cope'. I couldn't walk and to do the things I was meant to do to keep me heart well. And I thought it was all unravelling." (Margaret, interview 1, phase 1)

"Y*eah, we just got over the CF, and then was it asthma, wasn't it. Then we just got over the diabetes and then they decided she needed to have ... a gastronomy ...eee, I'll get that word right. So that was another thing on top and each time you think it's quite hard work. I mean she's no bother but you wonder where it will end ... she'll be needing a walking stick (*laughter). (Monica's mother, interview 2, phase 1)

The incidence of multiple pathology increased the level and amount of contact with many different formal carers. This appeared to increase uncertainty on two levels; firstly several medical conditions might require different treatments and needs, some of which may be incompatible (appendix 10, table 17 shows the technological dependencies of the children). For example, Monica took a photograph

of her bedroom with an electric pump feed, a nebuliser and insulin equipment next to her bed. Looking at the photo, she reflected on the challenges of being dependent on machines and injections;

"I got a tube in my belly and I got 7 teeth out just at the back. I've got cystic fibrosis and I'm diabetic as well. Just got a bad chest and stuff like that. Since the first day I was diabetic I control the blood sugar and have the insulin and take your BM and that."

Monica's diabetic treatment demanded a low sugar, low fat diet. However, her diagnosis of cystic fibrosis massively increased her energy requirements; the tension between the two very different requirements meant a daily balancing act and constant monitoring of blood sugar. The decisions about co-ordination of care were perceived as being "*left up to us*" (Lucy, interview 2, phase 2) by some participants, who were left with a feeling of never quite being certain whether decisions were correct or not.

Secondly, the incidence of multiple needs and the assistance required by participants engendered a tension between family life as private and personal, against having to justify life decisions and living arrangements in a very public way. Participants in phase one expressed this in terms of reluctance to accept outside help in the form of visits to the family home;

"Why it needed two (Occupational Therapists) *of them to come out here I don't know. Just they were very overbearing and unsympathetic, you know. It was really hard work to try and make conversation with them. In an artificial situation like that, when we were dying to get Catherine home and ... we had these two idiots who came and contributed absolutely nothing. After that, no more. I said no when they offered more strangers intruding on our private home."* (Catherine's husband, interview 1, phase 1)

Parents expressed this tension in relation to attendance at a child review held by the school each year;

"It's very formal and .. I didn't find it very comfortable and I didn't enjoy it and so I haven't been back since. They all sat there, these experts asking really stupid questions about my boyfriend and my laddie and such like and it's none of their business. If I want to smoke it's no-ones business. They're not living with the stress of .. a child with .. and I go outside anyhow." (Monica's mother, interview 1, phase 2)

Although the existence of multiple pathology appeared to cause uncertainty in relation to interfacing with formal carers, it also gave participants a sense of technical and practical mastery over the disease process and its biomedical needs. In particular, previous diagnoses seemed to be conceptualised as prior experience discussed earlier. For example, prior diagnosis of hypertension allowed for a knowledge to be accrued of the medical system, and relationships already existed with health care providers (see appendix 10, table 9). When a further diagnosis was given, prior experience seemed to reduce uncertainty about negotiating the health care system.

"I had a tumour in the breast and under me arm. I had the lymph glands and everything taken out which I got over remarkably well and ... I had 18 sessions of radium which, I was really poorly ... I blistered terrible bad and exactly to the year of that I took shingles right down one side again. But I mean I was fighting it and I knew the way things worked and that people were there to help. (Susan, interview 1, phase 1)

Initially, therefore, multiple diagnoses increased the experience of uncertainty concerning both the interface between formal carers and families, and the unpredictable path that the illness might take. However, it seemed that similarly to the process of using prior experience, a growing realisation that multiple pathologies

gave the opportunity to develop technical and practical mastery over the illness process led to reduction in uncertainty and increasing levels of predictability and control. Again, questionnaire data points to a contrast between this sense of mastery held by patients and carers, and the sense of deficit and accumulating needs held by staff, who responded to this deficit by wide referrals to members of the multiprofessional team. In practice, these referrals led to multiple home visits from various professional groups, a fact which seemed to erode and threaten the growing feeling of control and predictability over the disease process.

Consequences of uncertainty

Conflict
Hope
Loss of control
Biographical anxiety

The consequences of uncertainty have been referred to thus far in relation to loss of control. The following section clarifies the effects of uncertainty on conflict, anxiety, loss of control, hope, and inability to accept chronicity

1. Conflict

The uncertainty surrounding unpredictable needs often led to difficulty in mediating the conflicting needs within and beyond the family. For example, a child with cystic fibrosis is prone to chest infections that often require unpredictable admission to hospital. In both phases, this unpredictability created challenges within the family in terms of being unable to plan holidays and outings for siblings, needing to organise child-care at short notice for siblings, and financial difficulties precipitated by travelling to hospital and taking days off work;

"I think ... things have been affected, obviously. You just have to stand back and appreciate what's achievable and adjust your life style accordingly. In terms of work, it's affected in the sense that my job requires travel and ... I've tried to work it so that it feels ... so that I don't spend time overnight, where-as in the past, I might have spent a couple of nights in London. Now, I would fly down, fly back in the same day. So that can be more tiring than staying over night ... so it's a case of reorganising your work schedule" (Catherine's husband, interview 1, phase 1)

Stroke patients feared that they would become a burden on their family members by being dependent upon them and not being able to offer anything in return in terms of

what they had previously offered in the way of financial, physical and emotional contribution to the relationship. Equally, the informal carer identified by the stroke patient often feared that their care giving would in some way become a burden onto other family members;

'My life will obviously change, you know, depending on how badly affected he's going to be ... I can't rely on my daughter - she's got her own life to lead, which she will, knowing her, she'll help all she can but I wouldn't want to be putting on to her, you know. She's only young herself and she's going to have her life to lead so whatever has to come, I'm going to have to face it myself.' (Matthew's wife, interview 2, phase 1)

In both phases, the uncertainty about prognosis and lack of predictability over acute episodes led to difficulties in achieving a satisfactory balance of needs, thus threatening the stability of the family support network. This was particularly the case in families in which the chronically ill child had siblings.

"Toby's sister would love to mother and nurse him but he's ... too independent for that, yeah. They both tend to be a little bit bossy so they can play for so long and then ... she has to be careful because he's so fragile at the moment. I worry that he gets everything and she gets no attention and then on top of that she has to let him win every time. It must be hard on her." (Toby's mother, interview 1, phase 1)

Appendix 10 (table 14) indicates the family structure and living arrangements of the children in the study. For the children who had only older siblings or no siblings, it appears that their family structure had been influenced by the unpredictability and conflict engendered by their chronic needs. In other words, parents told me of a conscious decision not to have more children following the diagnosis of their child's illness since they felt they would not be able to cope with the extra layer of

competing needs brought on by a younger child. One woman even resorted to a termination of pregnancy, rather than have another child.

*"I was having a lot of problems and I was pregnant and unfortunately at that time there was no way I could have .. faced having another baby (*crying). *Had I had all this backup and help I now have, I would have had the baby but ... you can't dwell on that either. That one would have been six now."* (Rebecca's mother, interview 2, phase 2)

Several of the children lived with single parents or with step-parents and participants alluded to reasons for marital breakdown, involving an inability to balance the uncertain, unpredictable needs of the ill child with the needs of the marital relationship.

"It was too much for her (mother) *cos she's got us all to look after and then she's got .. her and me dad just were .. fighting. He lives in South Shields now."* (Monica, interview 1, phase 2)

Conflicting needs within the family appeared to add an extra layer of uncertainty about the unpredictability of unstable and acute needs and problems; not only was it impossible to prevent the incidence of these needs, but it was impossible to predict or control the effects of these on the family as a whole. Formal carers from each phase reported tensions in balancing the needs of the person with the needs of the family and often gave precedence to the needs of family carers over the wishes of the person themselves. The over-riding concern was again expressed as being with carer burden.

"I would assess how Mrs B is coping with her husband's illness and decide on realities of discharge home - what back-up and support they will need – consider other options." (Staff nurse 3, questionnaire, phase 1)

"Planned short home visit to assess carer coping and burden. Planned visit to residential accommodation if consideration of more sheltered living warranted." (Physiotherapist 2, questionnaire, phase 1)

Although the sense of carer burden was a recurrent theme arising from questionnaire data, respondents failed to mention financial burden engendered as a result of illness and caring responsibilities. Several of the carers in both phases reported either giving up their jobs or reducing their hours to devote more time to caring for the disabled person. The fact that carers found themselves unable to get any sort of financial help until a formal diagnosis of the person's condition had been made, was a factor in their decision to initiate medical intervention. For families in phase two, the process of gaining access to benefits was perceived to be extremely complex and time-consuming. This added to uncertainty and unpredictability about the financial burden of living with chronic illness. Isabel's mother told me,

"I could have had the benefits for Issy since she was 3 and I didn't know. All this time and I didn't know. I went down to see the headmaster and he said 'Oh I thought you knew." (Isabel's mother, interview 1, phase 2)

The emerging picture is therefore again characterised by a contrast between participants reaching a complex compromise to meet the needs of the whole family, not just the person with ill health, and the more simplistic view held by staff who again conceptualised family dynamics in terms of deficit and burden, while struggling to address the financial burden felt by families.

2. Hope

Uncertainty has thus far been presented as an entirely negative emotion, leading to conflict, anxiety and loss of control along the trajectory. However, participants sometimes chose to maintain, rather than eliminate, uncertainty by actively avoiding

negative information that would lead to a distressing certainty. The maintenance of uncertainty was therefore used as a conduit to hope for the future;

*"I mean the staff... if ***(*husband*) asked to see the Doctor to discuss my condition, which I think he did on two occasions, he was catered for, you know. They made every effort to make sure things were explained ... but generally I think, yes, I didn't want to hear it .. that I might not recover. So I did not go."* (Catherine, interview 2, phase 1)

Uncertainty about needs and ways of meeting needs was sometimes seen as a preferable state of affairs to having unwelcome certainty about formal care;

"The thing is, we were managing great and I didn't want any-one coming in and telling Ina what to do and what not do." (Ina's husband, interview 1, phase 1)

In addition, uncertainty about prognostic milestones was sometimes seen as preferable to being given definite facts about the future course of the illness;

"I didn't want Liam to be ... like, put in a box of what they thought he could do, like them telling me what my child was capable of. I was terrified they would say 'he'll never do this and never ride a bike and never have a job and ..." (Liam's father, interview 1, phase 2)

Participants sometimes manipulated uncertainty about prognosis as a way of maintaining a continued 'promise' of a cure in the future. This data contrasts with the more strongly seen data concerning the need for information, knowledge and experience and the overwhelmingly negative and crippling experience of uncertainty that participants were desperate to eradicate, particularly early on in the trajectory. However, participants, and particularly the children in this study, demonstrated that far from being overwhelmed by uncertainty and unpredictability, they were able to use uncertainty as a conduit to future plans that had no limitations placed on them by

the chronic illness. For example, Sam used a photo of his friend as a way to explore his familiar, predictable status within the school and his hopes for the future.

"That's my mate, Catherine. I'm a very popular person in here. Eye. I get on with her and ... I'm very popular with the staff here and all that. I've been here since I was ... was ... I think it was when I was five and now I'm at the top and people look up to me like. I want to be a policeman and if I want to get a job, if I stay on it might help me to get a good reputation, if you know what I mean."

Although the data on hope did not emerge as strongly or as frequently as the data on more negative consequences of uncertainty, it still deserves a mention in order to place the process of adapting to uncertainty in its full experiential context.

3. Loss of control

As discussed earlier, the chronic illness trajectory experienced by both patients and children was often punctuated by recurrent but unpredictable deteriorations in physical health, sometimes requiring urgent admission to hospital. In both phases, these episodes were characterised by the primacy of importance given to physical and medical needs in both the hospital and the special school. This emphasis on acute management of physical needs resulted in a feeling of loss of control over aspects of personhood such as the maintenance of social networks.

Even when acute episodes did not result in hospitalisation, they served as an unwelcome reminder of the illness course and this adversely affected the social and emotional lives of the chronically ill person and their family.

*"They all have their own work to do and they all have their own commitments. (*Starts to cry*) .... There's nobody like your partner. When I feel poorly you need help and you just can't get it without putting on people."* (Matthew, interview 1, phase 1*)*

The apparent lack of control over acute episodes led to difficulties in coming to terms with the illness and its effects. It seemed that participants wished for an illness with a constant course, even if that course had negative consequences. This was perceived as being preferable to the uncertainty of fluctuating needs and the occurrence of unpredictable episodes of acute ill-health.

*"And now the stroke and then all the swallowing problems and the chest infections. You wonder where it will end. This is really, really awful but my brother-in-law had cancer and died and in a way it was easier .. easier at the time 'cos you knew what you were playing with .. and you knew what would happen down the road. I'm sorry, you must think I'm really awful." (*Matthew's wife, interview 2, phase 1*)*

During acute episodes, participants commented on the frustration they felt at the primacy given to biophysical needs and professional knowledge that over-rode experiential knowledge of living with a chronic illness during its long-term phase.

*"All this physio is rubbish for a man of my age. I just want that social worker to get his finger out and get me a wheelchair and ... a ramp and such like so that I can go home to my wife. That's not asking much when you're 85, is it?" (*Thomas, interview 3 following readmission due to a second stroke, phase 1*)*

*'Monica is brilliant with her feeds and with her injections but the other week she went back in (*to hospital*) and they just took over so when she come out ... we had to start all over again with teaching and bossing to make her do it on time.' (*School nurse, observation period 5-Monica, phase 2*)*

This apparent conflict between physical and socio-psychological needs was felt particularly keenly by participants who had multiple health problems or more than one diagnosis of chronic illness. For example, following his massive stroke, Adam was observed showing signs of depression accompanied by a desperation to return home to his pet dog. He was making physical progress following his stroke, and his physician had decided that he would deal surgically with a long-term hernia

problem while he was in hospital. The intention of this was to improve Adam's nutritional status in order to facilitate further recovery from the stroke. Adam expressed frustration and sadness but agreed to this in the hope that he would recover enough to return home eventually. Although the operation was deemed a success by medical and nursing staff, Adam was transferred to a nursing home and developed a depressive illness that required psychiatric intervention. His daughter described him as a *"broken man with nothing left to live for"* and expressed frustration that although he was regarded as a success story in physical terms (having survived a devastating bleed in his brain). She told me:

"he's just waiting to die ... it's very sad ... why keep him like this? It's cruel, I think." (Adam's daughter, interview 3, phase 1)

In phase two, staff within the special school asserted the important given to psycho-social and educational-developmental needs over physical needs engendered by the child's illness. Despite this, a similar pattern of frustration and lack of control over the primacy given to physical needs was expressed by parents.

" I think, I'm not being funny but 9 times out of 10 you've got a bairn who's got a terminal illness and you want to know that they are learning and having fun and .. friends and that but all they (teachers) *talk about is how well the diabetes is .. and am I managing the flaming chest phsyio."* (Monica's mother, interview 2, phase 2)

"He was studying well and the physiotherapy department obviously didn't like it because they are feeling that in that case, he will losing his daily physiotherapy session which is vital for him. I prefer it well that. He has to do to be a doctor." (Hanif's father, interview 2, phase 2)

In contrast, children did not seem aware of this conflict and viewed nursing and physiotherapy sessions as seamless extensions to educational and social aspects

of their daily lives. This appeared to be the case even when repeated hospital admissions were necessary.

> *"Ask me about Ant & Dec. I love them. When I was in last time* (hospital) *they wrote me a letter and all the nurses were dead jealous. Sarah wasn't in last time* (in hospital) *but she probably will be next time .. I hope she will anyway ... I want to show her the letter 'cos she will not believe it. She's 12 but she doesn't come to this school."* (Lucy, interview 3, phase 2)

For Lucy and the other children in this study, hospital admission did not represent a negative reminder of her illness as it did for patients in phase one, it was seen as a social opportunity that did not conflict with other aspects of her life. The difference between experiences may lie in the fact that the children had to accept these acute episodes as part of their lives for such a long period of time. It is possible to suggest that patients in phase one may have experienced a similar acceptance had the study been able to follow them for a number of years following diagnosis.

This temporal element to accepting the illness journey is discussed in the following section in relation to the anxieties located within the past, present, and future illness trajectory.

4. Biographical anxiety

The lack of information regarding prognosis, coupled with the apparent struggle for diagnosis highlighted earlier seemed to lead to a background level of anxiety and uncertainty located on a time continuum; regarding past actions, present coping behaviours, and future needs. Retrospective accounts of the peri-diagnostic period

showed that participants experienced uncertainty regarding their actions prior to engaging with formal health services. For parents, and stroke patients and their carers, feelings regarding the past experience of illness focused on guilt and doubt about whether actions taken by either family members or formal carers had negatively influenced the diagnostic and prognostic outcome of the illness. Since there was no way of knowing for certain the effects of certain actions, this contributed to the experience of uncertainty concerning the past history within a participant's biography.

"It took a while though, didn't it? From start to finish ... it took about ... from start to finish it was about two or three year, wasn't it? All the red tape and all the rest of it, you know? ... Physiotherapy ... we often wonder if it had been started sooner it might be better like. For Jake, like." (Jake's mother, interview 1, phase 2)

With regard to the current experience of chronic illness at any given time, carers' feelings focused on whether caring actions were the 'right thing to do' or whether they in fact might make the situation worse.

"The only bit I'm worried about ... the physios are more firm than I am. They make her try. She is supposed to do exercises and practice walking and things like that and I used to say are you going to have a bit wander around the house ... oh, I'll do it after tea, oh, I'll do it after supper, I'll do it tomorrow and it very rarely got done, you know. I didn't like to press her. So I hope the physios press her a bit harder than I do." (Ina's husband, interview 1, phase 1)

With reference to both children and stroke patients, they did not report any feelings of uncertainty in this regard and seemed unable to focus on the present experience of illness in terms other than normalising strategies. They were able however, to express concerns over the future. In phase one, patients expressed vague

anxieties about uncertainties of the future in relation to both their family's continued ability to cope over time, and their own possible deterioration in health.

"Me daughter - she's had heart and lung transplants and she's generally down with migraine but this day she was up. Well, I think so, she had her clothes on when she came over and she was dressed. But I think if I get worse and she cannot cope with it all, I'll have to go into them homes. I cannot do it to her." (Susan, interview 2, phase 1)

In phase two, parents worried about how their child would manage without them when they themselves were in ill health or died. This underlying fear was precipitated by the level of uncertainty about their child's physical prognosis.

"But he's growing up and in one respect that frightens me.... I've got one nightmare. I suppose that other parents with disabled children would feel the same way as well. My main fear of life is ... if anything happens to me or my husband, where would Billy end up." (Billy's mother, interview 1, phase 2)

Children expressed uncertainty over future acute episodes in terms of whether they might need surgery or how a hospital admission might impact on their social worlds, but otherwise had hopes and dreams for the future that were not blighted by the possible effects of their impairments.

*"Monica's in hospital I think. She was supposed to phone but Mrs**** said she was in hospital. I hope that doesn't happen to me. I've been in once for me back and that was enough."* (Simon, interview 1, phase 2)

It seems that while the time continuum was a vital part of understanding the effects of chronic illness on the person, staff interventions were very much focused on the present or near future. This emerged as strongly in the school phase as it did in the hospital data. Overwhelmingly, staff reported that they would make decisions based

on information they had at the time to intervene in relation to short-term goals. Contrasting with this, in both phases, physiotherapists were very focused on long-term physical aims.

"*My long-term aim would be to work for maximal functional ability to enhance independence.*" (Physiotherapist 1, questionnaire, phase 1)

At no time was there any mention of the person's past biography from formal carers in relation to the pre-diagnostic or post-diagnostic period.

During phase one observations, patients were often heard asking direct, closed questions about their prognosis such as *'Will I have another stroke, Doctor?'* (Susan, observation period 1, phase 1). These questions were not answered with a direct yes/no reply. Replies tended to be directed towards telling people not to worry about the future and maintaining general hope that everything would go well. Interviews with patients and carers indicated the uncertainty and frustration experienced as a result of this apparent lack of discussion about the future. For example, Anne's daughter told me:

Yes, it's affected her right side so I think this is where Mam's going to sort of ... but I mean apart from that really, apart from such as you, we've got nobody to talk to, you know like, in the hospital, you know, so therefore you're more-or -less left up against a blank wall really. But ... I know my Mam has had a stroke and they explain so much but they leave so much out'. (Anne's daughter, interview 1, phase 1)

Analysis of these issues fed into data collection in phase two which showed that although the children themselves were largely unaware of their diagnosis and prognosis, their families maintained open dialogue about the ways in which needs and problems might be experienced in the future in relation to social and educational

development. This contrasted with the emphasis on technical and bio-medical information by participants in phase one. Parents expressed their fears and anxieties around the diagnosis in terms of wishing to find out why the illness had occurred. Where information was available, such as in the case of cystic fibrosis, it seemed to confer a level of control over subsequent pregnancies. This allowed these families to make informed choices about the future and opened the channels of communication between families and staff in a positive, supportive way. It also provided a way of creating some positive meaning from the illness in the sense that their child's diagnosis meant that another family member might be prevented from having this illness.

"The two girls might be carriers but we don't know yet. I mean I think they will want to know actually cos they wouldn't want to be getting married and then find the other person's a carrier. I never knew I was a carrier. It was unheard of 10 years ago but at least we know now for the girls. At least they won't have to go through this like we have." (Monica's mother, interview 1, phase 2)

In contrast, several children had chronic illnesses for which medical science have yet to locate a definitive cause (for example, cerebral palsy). During the diagnostic period, this caused parents some anxiety and uncertainty in relation to blame and guilt that they may have caused the illness to occur.

"I .. I had very high blood pressure up to six weeks before but... I was on ... the sickness drug .. the one all the fuss was .. Debindox. And I was actually on it when the scandal came over from America .. so I was actually taking it then and they were withdrawing it in the States ... so I've always felt .. guilt I suppose that I didn't go into it more before I started taking it." (Rebecca's mother, interview 2, phase 2)

Just as people felt uncertainty and anxiety about past actions, participants also feared that in the future they might realise that they hadn't done something correctly

or that they had missed some important piece of information or treatment that may have benefited them in some way. In particular, participants expressed concern about needs they might experience in future that they had no knowledge of at the present time; "*You don't know what you don't know, do you pet?" (*Andrew, interview 1, phase 1*)*. Conversely, people also feared receiving bad news about their prognosis or an unavoidable change in their treatment over which they could exert no control such as a change in special educational policy. This caused anxiety when interacting with formal carers.

"I mean some people maybe find it too much to sit in the room with experts. You don't know what is coming and they might say Issy won't ever do .. and that would be very hard. The other thing is this about special ... schools I wish the .. Government would leave alone because every time I go I think are they going to tell me Issy has to move again. I feel .. afraid for her" (Isabels' mother, interview 1, phase 2)

Uncertainty was therefore firmly located within an imaginary life-journey incorporating information, knowledge, understanding and care delivery in the past, present, and future of the chronically ill person.

Conclusions

This chapter has located the causes of uncertainty within the unfamiliar, unpredictable illness trajectory. At an early stage of the illness, participants experienced heightened uncertainty about the origins of symptoms and the most appropriate responses to those symptoms. Following diagnosis, participants then expressed uncertainty and confusions about the failure of the acute system to provide a cure or to adequately meet the biographical needs of the person and their family.

Uncertainty about the ways in which needs would fluctuate and would be responded to with a social, physical, and organisational context poorly equipped to meet chronic needs created the experiential background, against which participants made difficult decisions about the most appropriate ways of meeting needs. In this study, uncertainty led to loss of control, conflict, hope and biographical anxiety within and beyond the person with the chronic illness. These consequences influenced the ability of participants to gain mastery over their illness trajectory in relation to mediating the effects of unpredictable needs within the family unit. Over time, participants began to develop increasingly sophisticated strategies for dealing with the uncertainty inherent within the illness trajectory. These processes, described in the following chapter, involved making comparisons with others and with the biographical self in order to maintain a sense of person-hood and biographical integrity. This was augmented by the use of normalising strategies that allowed families to balance the needs of the chronically ill person with the needs of the family unit in a way that ensured the illness did not define every day life.

Chapter 8

Management of uncertainty at the interface between chronically ill people, their carers and professional staff

Introduction

The previous chapter elucidates the causes and consequences of uncertainty and locates this description firmly in the contextual world in which participants lived and worked. It emerged that participants did not passively accept the uncertainty inherent in their illness trajectories, but that a complex series of psycho-social processes and interactions were used in order to actively manage uncertainty and incorporate it into the biographies of participants. This chapter presents three inter-dependent processes that were undergone by participants in order to manage their lived experiences of uncertainty. These processes, shown in figure 9, were firmly located in the social and temporal worlds of participants and focused on the psycho-social exchanges between members of the care-giving/care-receipt triad. Analysis of the strategies resulting from these exchanges led to the identification of the process of understanding, accepting and adapting to uncertainty across the illness trajectory. The first process, referred to as the process of **understanding,** involves mapping one's own trajectory in order to gain mastery and understanding of the illness course. This map-making process involved firstly a series of comparisons between people with chronic illnesses in order to locate the severity and course of an illness. Secondly, comparisons made within one's own biography were adopted in order to gain mastery over the present within the context of a challenging past, and an uncertain future.

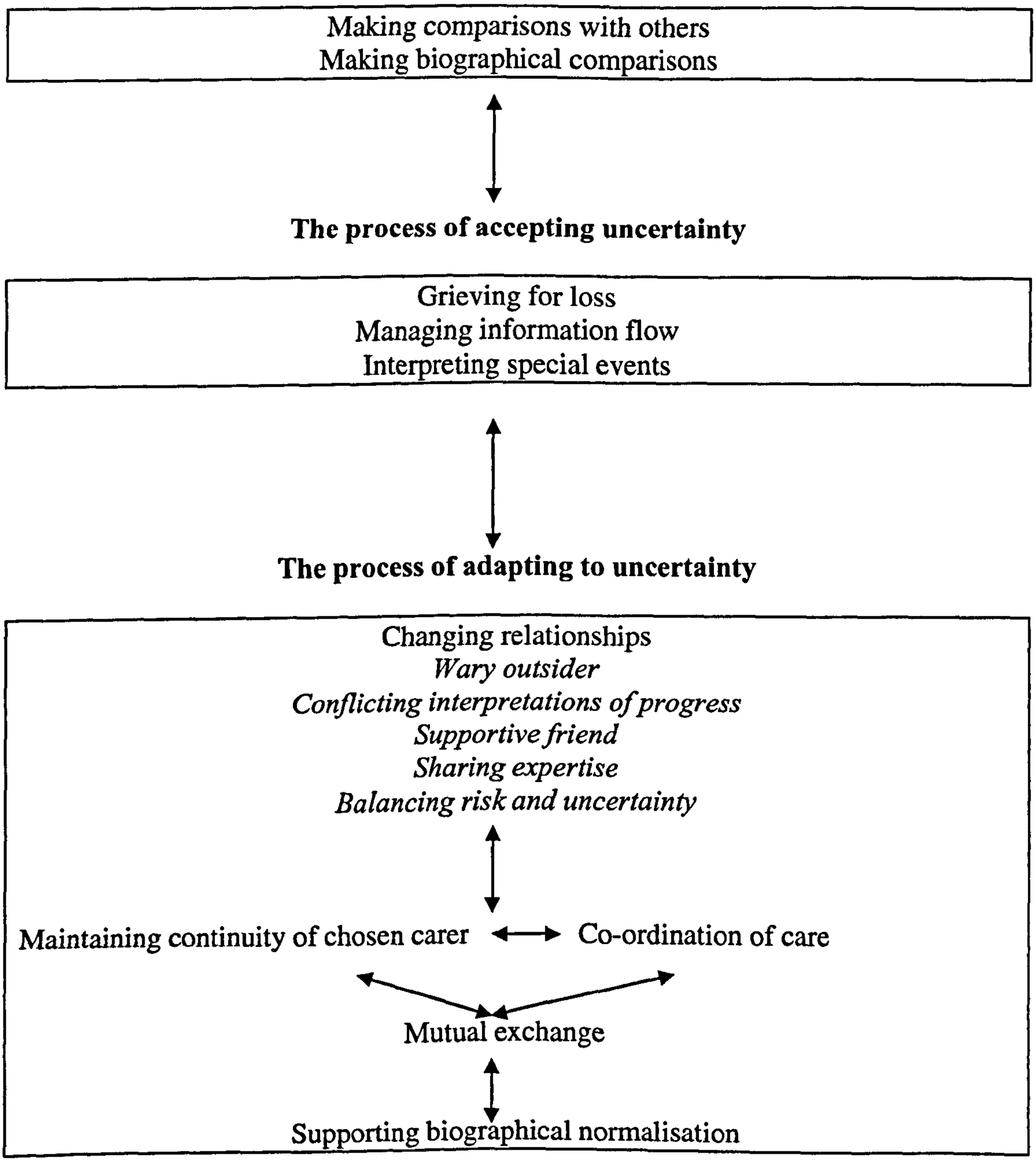
The second inter-dependent process, the process of **accepting,** was used by participants to make greater sense of the uncertainty inherent in the illness trajectory. Once participants understood the limits of the prognostic capabilities of professional

staff, they began to reach an acceptance of the existence of this ongoing uncertainty by managing the flow of information. This management involved drawing from the multiple information sources available to them in order to make sense of the illness trajectory within the biography of the chronically ill person and to reach an acceptance of a new normality that embraced the uncertainty and chronicity inherent within the illness trajectory. Successful management of information flow reduced uncertainty and unpredictability and then allowed participants to employ a subtle process of normalising the present situation at any given time within the illness course in order to maintain identity and a sense of purpose and control over unpredictable needs and environments.

The experience of managing uncertainty and accepting chronicity was carried out against a background of changing relationships between chronically ill children and adults, their family carers, and the professional staff working to meet their multiple needs. This set of relationships, the interface triad, influenced representations of the experience of uncertainty and chronicity in several ways, presented here as the third and final process of **adapting**. Professional staff moved from being seen as 'wary outsiders' to the family unit, to being 'supportive friends', depending on whether an acute, curative or a chronic, restorative model was adopted within the triad. The two main strategies used to manage the process of adapting to uncertainty were maintaining continuity of carer, and engaging in a system of mutual exchange in which all members of the interface triad benefited from the care-giving / care-receipt relationship. These strategies were located within the ability of all members of the interface triad to openly accept the chronicity inherent within the

illness trajectory, and the ability of professional staff to support families within the context of uncertainty.

Figure 9: **The theory of living with uncertainty**



The Process of Understanding Uncertainty

Making comparisons with others Making biographical comparisons

The process of understanding uncertainty involves an inter-dependent combination of comparisons with others and with the biographical self in order to locate oneself on a personal illness trajectory. This personal location was a necessary reaction to the context of both fluctuating and constant uncertainty, described in the previous chapter, about the cause, diagnosis and future course of the illness, and the limits of technical, medical and prognostic information that was possible at any given time. This section describes the process of making comparisons with others before going on to elucidate the process of making biographical comparison. These strategies allowed participants to become familiar with the illness trajectory and to begin to predict their needs and the ways in which these needs would be responded to.

1. Making comparisons with others

Following diagnosis and subsequent placement into a path of service provision, participants in each phase attempted to reduce their anxiety and increase their level of knowledge and understanding about the illness trajectory in two main ways, by; a) befriending people experiencing the same service provision and/or diagnosis, and b) going through a long-term process of comparing and contrasting their own experiences with those of their new acquaintances.

In the hospital site, the process of comparisons was found to be equally important to the stroke patient and to their family carers. Family members sought out families of other stroke patients on the same ward, and this process was inadvertently facilitated by strict visiting times that saw visitors waiting for the wards to open. While waiting in the corridor, carers chatted and asked about the progress of each other's family member. This progress became the benchmark for the progress of their own family member to be measured against, particularly in terms of the chronology of events and physical progress.

"Oh, yes. At first he couldn't sit like that, he was going over where now he sits like that (sits up straight to demonstrate). *Like Mrs**** *in the next bay. Once you can sit I think you're on the road like and hopefully we can get him home soon."* (Adam's daughter, interview 1, phase 1)

The patients themselves were instrumental in this process of identifying and comparing the progress of other stroke patients;

"As far as the stroke's concerned, I know nothing about them apart from what you hear from other people in the ward who's had them. There's him over in the opposite bed and there was a fella in the next .. what ya call it .. bay." (Andrew, interview 2, phase 1)

Patients and their family carers always used this comparison to conceptualise themselves as better off than others in terms of physical parameters. In other words, they never saw themselves in a worse state than others, despite evidence to the contrary. Again, the organisation of ward work inadvertently facilitated this process. For example, Ina and Anne were admitted to Ward 6 within a day of each other following massive strokes. They were allocated to adjacent beds in a 6-bed bay, the other beds being empty at the times of admission. During observation, instead of

drawing the curtains around each bed separately during washing and dressing, two nurses came and drew the curtains around both beds, leaving the dividing curtain open so that they could work between both beds. Neither patient were able to speak at this point, and were washed and dressed in full view of each other. Later, I asked one of the nurses about this and her reply was:

"Well, pet, you can see how busy we are. This way it saves time. You're not going to tell Sister, are you?" (Auxillary nurse, observation period Anne 3, phase 1)

I did not "tell Sister" but instead made certain that I included this incident in my interview schedule with Anne as soon as she was able to speak. (Sadly, Ina did not regain her speech and died some months later at home). Unexpectedly, Anne found the daily regime of washing and dressing her only contact with other stroke patients and as a result was fascinated by how much progress the other patient was making in terms of physical ability. The fact that Ina made little progress seemed to help Anne see her own situation in a different light and she took comfort from the fact that she herself was improving tiny amounts every day in comparison with the other patient. She, like the majority of the other patients, spoke in terms of being *"better off than others"* and drew hope and comfort from this fact. Ina later died; when the next patient was admitted to the bay, the washing procedure of drawing the screens around both patients was continued. Interestingly, Ina's husband perceived *his wife* to be improving more rapidly than Anne. He told me that he had often watched the stroke patient in the bed next to his wife and had drawn comfort from their situation.

"Well, you know, Anne being in the next bed has been a funny experience. I don't know whether it has helped me or not, I don't know. Except to see someone worse off than Ina, poor soul. I wouldn't wish that on anyone but in a funny way it helps us at least count our blessings that Ina's not as bad as that. The other thing is that you

think well, if they are bothering with her, a much worse case, not like putting her on the rubbish dump, then there must be a chance for us, for my wife". (Ina's husband, interview 1, phase 1)

On another ward, Mrs. Smith told me, *"There's not many in with strokes at the moment. They are nearly all heart attacks in this ward. You find out, you know, as you go along. It's good because you can watch and think, well, I'm not as bad as that, which is ... awful really, but a heart attack is really painful where with a stroke, there's no pain. And then I watch them all going to physio and I think there but for the grace of God go I."* (Sally, interview 1, phase 1)

The physical impairment experienced by a stroke patient is often much worse than that precipitated by a heart attack; even so, this patient used comparisons to conceptualise her journey as a positive one in terms of physical prognosis. There was no evidence of phase one participants using this process and concluding that their prognosis or physical impairments were substantially worse than those around them.

A similar pattern of comparisons made by both children and their parents emerged in phase two. In contrast to data from phase one, comparisons were made not only on the basis of physical or medical parameters, but also educational and social developments. The process appeared more complex in phase two and involved a recognition of positive comparisons, as well as a process of managing and discounting negative comparisons. The differences between each phase in this regard are unclear but may be located in the length of time from diagnosis to the commencement of the study. It is possible to suggest that in phase two, the greater time period saw participants come into contact with large numbers of chronically ill people, information about whom needed to be managed and located within the child's own trajectory.

Without exception, and without direct questioning, families identified a set of children with the same diagnostic category as their own child.

The physiotherapists ... well there's 6 lads I can think of with this dystrophy disease ... so the physios and the teachers must sort of get to know the case. There's Liam and Peter in his class with the same thing so he doesn't feel so different." (Jake's father, interview 1, phase 2)

"When he was nine, he went to Disney Land with the school and on the passport, it had "any distinguishing marks?" The teacher always laughs because she had wrote down "24 scars on the left leg", 'cos they all have this biopsy to diagnose Duchenne. There's quite a lot with this illness. There's Liam and Jake and Arrif and Arrif's brother and ... all lads, like." (Peter's mother, interview 1, phase 2)

Some of the children were able to identify friends who shared their own diagnostic label, but were usually unable to identify other children's diagnoses if it did not match theirs. Not only could they identify a set of children with the same diagnosis, but they also compared each child in that set with themselves and each other in terms of physical and academic ability. In contrast to the way in which positive physical comparisons were made by the parents in the study, this comparison did not always place the physical progress of the child in a better light than those around them. Peter told me,

"Arrif got done when he was about 3 ... to get the test for M.D., then they knew his brother, who's called Iqbal, might have it and he has ... but not as much as us. He can walk even without callipers. Liam's younger than me but he's got it worse and he's already had the operation to straighten his back." (Peter, interview 1, phase 2)

Some of the younger children were also able to demonstrate this process of comparisons, as Kate, a 7-year-old, explains:

"Tom has brittle bones but he's a lot older than me, he's in class 11. He's not as bad as me, he only uses a wheelchair outside of school. My mam .... my sister's a carrier. If she has babies she might pass it on to them. My cousin's got it. She's one year older than me but she doesn't come to this school and she can't read as good as me." (Kate, interview 1, phase 2)

This process of comparisons allowed the children to make sense of their ability or inability to 'fit' in to mainstream education. Comments about transfer on the whole were positive, with several children referring to their relief at finally being in an environment where they did not feel "*different*" (Monica, observation period 3 in residential unit, phase 2). Peter reflected on a photograph of his class mates and told me,

"At Smithson school you get treated equal. I mean you've got to work and you are just treated the same. I didn't like the junior school (mainstream) *because they used to make a right fuss."* (Peter, interview 1, phase 2)

On a separate occasion Peter's dad told me,

"They wrapped him up in cotton wool, didn't they? He piled the weight on with the dinner ladies being so soft. They would say "Aah, here's Peter, we'll give him a big helping", then when he went to Smithson ... he was treat like normal." (Peter's father, interview 1, phase 2)

Families became aware of the diagnosis of other children by firstly talking to other parents at open nights and other meetings within the school, and secondly chance meetings with other parents while the children were in a hospital ward or in an outpatient department. The parents used these meetings to gain information about the progress made by each other's child. They then used this information to place their child within the illness trajectory in relation to their own child's past and possible future experiences. For example, Jake's mum told me how, following advice from their consultant, they did not expect Jake to live past his 15th birthday. When Jake joined the school, he met Tim who had the same diagnosis but is now almost 21. Jake's parents drew hope and encouragement from this fact and Tim's life became

the focus of much interest and discussion in Jake's household. This experience was mirrored in Kate's account of meeting others with Brittle Bones disease;

"We're going to Peterborough for the summer holidays where the Brittle Bones Society is. With my aunty and my cousins. My little cousin and two big cousins. My sister's going to go next year 'cos she's not old enough to go this year. Last year there was a treasure hunt and no-one was rough and we were all gentle and some children was in plaster so we signed each others casts. Usually I get a friend to play with at the discos." (Kate, interview 1, phase 2)

There were many more examples of parents and children alike seeking out children with a similar diagnosis, a process facilitated by organisation of therapies for the children. For instance, Debbie and Ruth both suffer from juvenile rheumatoid arthritis and received regular physiotherapy, including swimming, together. They provided support and encouragement for each other in what was often painful and distressing therapy. Although neither girl could tell me the name of their illness, they knew that they each had the same problem, and each was able to identify which child was the worst affected.

"Well, Jane's my physio and she comes and gets me and Ruth. Michelle does Ruth. Jane does me and they stretch us. Sometimes Ruth gets a bit upset cos she's worse than me and it hurts her bones. I hope I don't get worse like that. We've both got something wrong in our bones but I'm better than Ruth. She's more sore." (Debbie, interview 1, phase 2)

During observation Ruth confided that:

*"We've both got junile art.. I canat (*sic*) say it. I can swim better than Debs. My legs are longer."* (Ruth, observation 4, phase 2)

The fact that both girls shared therapy times and formal carers facilitated the process of making comparisons by allowing the families to meet informally while waiting to see their daughters' physiotherapist on open days. Observation and questionnaire

data indicates that the organization of work and therapy times was done simply to streamline the workload of staff and the fact that it facilitated a coping strategy was nothing more than a positive by-product. Staff saw the informal meetings and friendships that occurred as a result of this organisation of work simply as a lucky side-effect of the system, and no organisational attempt was made to facilitate these friendships when the next school year required a rethink of the staff timetables.

For some parents, the process of comparison was a source of constant hope and support. For example, some parents found that their disabled child compared very favourably in terms of academic ability to other children of the same age.

"In my country, he has got no education system. No way of knowing if he was ... clever. But here .... now we know he is a brilliant boy. More brilliant than his brothers ... who are not ... in a crutches and wheelchairs". (Hanif's father, interview 2, phase 2)

"I've seen other children and I've always said, if I've had to have a disabled child, I've been lucky because there's a lot worse off than Lucy. I think I'm lucky because she's got intelligence." (Lucy's mother, interview 1, phase 2)

In contrast to phase one in which all comparisons of physical and prognostic progress had favourable outcomes, one parent did appear to compare her child's physical impairments and future prognosis unfavourably with others and therefore avoided opportunities to share experiential knowledge with other parents.

"I've boycotted that Mothers group at the school. Not deliberately but personally it was at a time when we were having problems and I said look I don't think I can come down and sit with other people's problems. I need more .. incoming help. I feel it would start me feeling depressed if I did that, you know looking at other people's problems sort of in that way and knowing how bad Becky is compared to their child." (Rebecca's mother, interview 1, phase 2)

Organisational influences on making comparisons

It seems that several of the ways in which organisation aspects affected this coping strategy were by-products or lucky accidents; However, several aspects of the organisational context were geared towards assisting people to make comparisons. A factor which influenced the process of comparisons by parents was the introduction of the National Curriculum. This curriculum was devised as a statement of educational entitlement that is made available to all children, with or without special educational needs. In this study, this shared language enabled parents for the first time to directly compare the educational achievements of their child with that of other children.

"The report that came had her quite low on the curriculum really. It didn't cover everything, you know,... but it sort of put it as if to say well we do know basically where she is and she is lower on those things than she should be. I had the scale from her brother, who's 7, and I checked it with that ... and it was more or less the same for Rebecca, so you can tell something from that." (Rebecca's mother, interview 2, phase 2)

This was very important to families because, in some ways, it enabled them to guess what the future might hold for their child in terms of job prospects and becoming an independent adult, and therefore mediated the uncertainty experienced. For some, this process of comparison was depressing in that they could not see a positive future for a person who was not educationally able. The arena of academic achievement brought a new element to the data on comparisons in that for the first time, about half of the parents were forced to acknowledge that their child was 'worse off' than others in terms of this academic comparison.

"It is quite ... you know, you try not to look too far ahead. I mean a normal job's out. But saying that, I think firms take in disabled people more now because of the laws,

don't they? But I am concerned because I think we will have to look for a residential place for her as we get older." (Lucy's mother, interview 2, phase 2)

In phase one the process of making comparisons with others was facilitated by attendance at a group held in a day room off one of the wards, set up by one of the staff nurses for stroke patients. Patients were given the opportunity to attend this group twice a week for 2 hours in the afternoon, the aim of which was to give patients a change of environment away from the clinical area and a chance to meet other stroke patients from other wards for support and encouragement. This was open to patients both during their hospital stay and following discharge from hospital. Observations carried out during one of these sessions indicated that several people were still attending this club years after their stroke. It is possible to suggest that, for these people, the strategy of making comparisons in order to relieve uncertainty about the illness trajectory remained important long after diagnosis. There was also evidence of a desire to help others in the same situation;

"I remember how traumatic it was to be well one minute and be devastated by a stroke the next. If I can help people by showing them how much you can improve then all the better." (Observation 1 stroke club, phase 1).

Attendance at the club appeared to provide friendships, mutual support and the opportunity to watch the progress of others.

"I started going down to the Fab club once I got me balance a bit."
H. The Fab club?
"Eee, I don't know if they call it that. It's downstairs, the little room with the nurses and once I got me balance I started going down there since last week which has been very good because they are wonderful down there. Oh, they are lovely people, they help you on all ways, all aspects but I enjoy it and then we try dominoes and that and with the risen up numbers and that but I used to enjoy it because you're meeting people with the same as you that you can look and see how they got on." (Susan, interview 1, phase 1)

It appears that the processes of information seeking and making comparisons with others allowed participants to place themselves or their loved ones on an imaginary illness trajectory in order to make sense of the present and make predictions for the future in relation to the unpredictability and uncontrollability of needs and problems. These predictions assisted participants to manage the prognostic limits of medical information and to come to terms with the fact that their illness and its physical impairments would continue to affect their lives in the long-term. This acceptance of the temporal aspects of the illness trajectory is discussed in the following section.

2. Making biographical comparisons

As well as the process outlined above of comparing the ill person with others, a parallel comparison occurred within the self; participants would compare needs and impairments experienced in the past and the present moment in order to make projections about their future needs and difficulties within the illness trajectory. Similarly to the above process, this process of intra-comparisons rarely resulted in a negative assessment of progress.

*"Dr**** came in and said to me in the hall, he said your husband's very ill you know. I said oh, I know he's not well. He said he doesn't really have a long time to live. So that when he started to sit and now he can stand for half a minute I thought well, he's a lot better than he was before, he's loads better than he was before. And I think we'll be able to get him home if he continues like this."* (Thomas's wife, interview 2, phase 1)

This psychological coping process was very important in conferring control, certainty and predictability in peoples' lives in relation to placing themselves on the

time continuum that represented the illness trajectory. This allowed participants to reach an acceptance that their illness was indeed chronic, and would be part of their lives for the indefinite future. Paradoxically, the process of understanding the *uncertainty* of the future illness course allowed participants to confront the *certainty* of chronicity.

In phase one, the study design (from diagnosis through to one year post-stroke) allowed for a picture to emerge of the ways in which the fear and expectation of chronicity caused patients and their carers some discomfort until an acceptance of the long term nature of the illness was reached. Fear of enduring problems was expressed in a sometimes desperate attempt to get information about prognosis.

"There's always the fear of it happening again. That's sort of there. You know, I'm trying not to think about it and people have told me it's a one off thing, you know, there's no reason why it should happen again, but if you knew why it happened in the first place it might help." (Catherine, interview 3, phase 1)

In every case, an awareness of ongoing chronicity occurred gradually and was expressed in terms of '*getting on with things*' (Rebecca's mother, interview 1, phase 2). This allowed patients to extrapolate their past and present experiences of the temporal nature of their illness in order to make projections about the future likelihood of the illness remaining part of their lives.

"It is ... because ... I don't think in the community, especially on estates, you know, like our estate, an old person is just sort of left unless they are in sheltered accommodation or in a home, they are just sort of left. To me they are ... which is the worrying thing, you know. It is ... But I think that's a bridge we'll have to come to, you know. It's quite a long way into the future. It's going to be quite a longish job, you know." (Anne's daughter, interview 1, phase 1)

Participants from the school experienced a much longer period of time following diagnosis to the time the study began and for them, the temporal nature of the illness was a fact that they had lived with for some time. This was expressed in reminiscences about the biography of the children in relation to the illness.

"*When she was first born, they weren't sure whether she would live or not and unless she progressed .. and then they discovered she had fluid on the brain. They said she might not grow as much – the size of her! Then they said she wouldn't have much concentration with the pressure on the brain, you know, and she would have a bad memory. And I think, well everything has been cancelled out because if you tell Lucy something she'll never forget it.*" (Lucy's mother, interview 2, phase 2)

The importance of biography within reports of chronicity emerged as strongly in the school setting as in the hospital. Parents and children augmented this biographical placement with attempts to compare their child's development in the past with present achievements in order to make predictions about the functional and physical abilities that may become apparent in the future. For example;

"This has been since she was born really. A normal 15 year old you would leave. It's all these sorts of problems that are more apparent now than they were 5 years ago. There's more problems really I think in the last few years than there was in previous years .. as she's getting older. It is terminal in a way because its not going to go away." (Rebecca's mother, interview 2, phase 2)

"Well, when you're born you can walk but when you break your leg you don't get up again and walk so you have to be in wheelchair all your life." (Kate, interview 1, phase 2 talking about brittle bones disease.)

In these examples, the temporal nature of the illness experience might have been expected to confer more complete and more positive adaptation to the illness. However, in contrast to the experiences of stroke patients and their families, the usefulness of this process was perceived to be hampered by the childhood

developments that took place independently of the chronic illness process. For example, a child with cystic fibrosis has an expectation of chronicity that ends with death at the early age of 30 years old (Lewis, 2000). Parents found this fact hard to accept when their child was developing well physically, emotionally and cognitively in ways that were independent of the disease process, and had difficulty in making accurate predictions about the future in terms of physical and functional impairment in the face of an otherwise 'normal' child.

"I don't know what the future holds for Lucy. Like I say, we thought she would die at home when we brought her out of hospital. But she's progressed so well and she's bright and she's progressed ever since. In a way it's hard because work-wise we've spoilt her. I think she could do anything she put her mind to but at the same time we thought she wouldn't get this far so we haven't pushed her academically or ..physically." (Lucy's mother, interview 1, phase 2)

This then hampered their acceptance of the long-term nature of the illness, and contributed to the uncertainty and unpredictability inherent in their child's future.

"You do wonder what he'll do when he's older 'cos we've accepted as a family like, that he's always going to have problems and you just get on with it. I worry in case his sister has to have a lot .. to do with it when she gets older like." (Sam's father, interview 1, phase 2)

Despite this difficulty, biographical comparisons allowed participants to gain an understanding of the prognostic limits of information available to them about their own illness. This then led to an active process of acceptance of chronicity. This is discussed in the following section.

The Process of Accepting Uncertainty

Grieving for loss Managing information flow Interpreting special events

The process of acknowledging and understanding the fact of uncertainty about the past, present, and future course and management of the illness occurred gradually. The important transition from understanding to accepting the inherent uncertainty was made by every participant at different stages of the trajectory and was influenced by the factors outlined earlier in relation to prior experience of illness and the presence of multiple pathologies. The process of accepting uncertainty began with an acknowledgement of loss of 'normalness' following a diagnosis of chronic illness.

1. Grieving for loss of 'normalness'

All participants except the children related difficulty in accepting the loss and changes brought about by the chronic illness. Participants held onto an image of "*normalness*" (Catherine's husband, interview 1, phase 1) that represented their lives prior to the stroke, or the imagined perfect child in the womb. When patients reflected on the first few days in hospital, they often talked about their sadness and fear at being with people with obvious physical disabilities.

"It was very depressing and I suppose soul destroying as I said. To see all the illness and suffering." (Catherine, interview 2, phase 1)

"It's just this past two days, he's been just that bit depressed. I think it's the cases that they've got in the ward is a bit morbid and there's none that he can, not that he can talk very much but it would be nice to have someone to have a bit chat with." (Matthew's wife, interview 1, phase 1)

"Normal" was a word used by almost all of the participants in phase one as a way of expressing their heartfelt wish to return to the way things were before the stroke. The definition of 'normality' was different for each person, although each person had a clear idea of what was normal to them, and which aspects of their lives they particularly cherished and wished to return to.

"I miss the contact with other mothers at school and I think I would like to get back to that. I mean I said to you that the children use the school bus now. That's something I didn't want to do ... because I think it's important to maintain, sort of, the links with the school and you can certainly do that by being there each day. That for me would be returning to normal." (Catherine, interview 3, phase 1)

"At the moment, the one thing that worries me is ... her mind. The rest I'm not worried about, you know, about anything physical, I can either handle it myself or have help to do it but ... as long as her mind comes back, then I'll be back to normal and I'll have my wife back." (Ina's husband, interview 2, phase 1)

The parents referred to their sadness and loss when they discovered their child would not experience a "normal" childhood. This sadness was expressed in relation to difficulties in carrying out activities that would have been unproblematic for a child who was not affected by a chronic illness.

"It's just the devastation of watching your son deteriorate before your eyes. Not being able to take him to the football and having to leave him in resi. That's the hard thing. (Liam's father, interview 2, phase 2)

Difficulty in accepting a different type of normality characterised by uncertainty was expressed in a variety of ways. Typically, when things went wrong or if people had a bad day emotionally, the client often felt responsible and would place the blame for every negative thing on themselves and their disability.

"I think he (husband) has had two bad days since it first happened. Unfortunately, I had a bad day at the same time which made it worse and I think he would have benefited if he could have gone out ... away from things ... but he had to stay and do everything for me which made it worse. He was feeling everything's on top of him. I'm feeling responsible for him feeling that way, which I am to a certain extent, so it's terrible, really." (Catherine, interview 2, phase 1)

The children in the study were by far the most accomplished group within the study at balancing their conflicting needs and ensuring that their sense of personhood remained firmly located within their social and emotional worlds. For example;

"It's too much for my mam 'cos she's got us all to look after. I hate the pump. The noise and that but I just connect it and go to sleep now." (Monica, interview 2, phase 2)

The reasons for this remain unclear but may be located within the sense of chronicity that these children had in which their illness journey was firmly located within their biographical stories. This contrasts with the patients in the study who suffered biographical disruption due to the shocking and acute nature of the stroke, and this resulted in difficulties in balancing their own needs and the needs within the family unit. Participants managed this difficulty by controlling the flow of information about their illness and its management. This is discussed in the following section.

2. Managing information flow

The process of managing the flow of information both to and from the chronically ill person and their carers augmented the process of making comparisons in order to

accept the uncertainty inherent in the illness trajectory. The making of comparisons often led to recognition of deficits in knowledge and information that were addressed by managing the flow of information in ways that maintained hope and positive acceptance of uncertainty.

The process of managing the flow of information began in both phases by recognition of a need for experiential and technical knowledge in order to make sense of the loss of 'normalness' alluded to earlier, alongside the recognition that a new normalness would have to be created organically rather than be something lived as a set of predicted milestones.

In phase one, several courses of action were described as being taken in response to the mini strokes. Firstly, the patients ignored the symptoms, which usually quickly passed. In all but 3 respondents, a second and sometimes a third T.I.A. was then experienced, symptoms and physical needs of the person being dealt with by family and friends. During this time, information and help was sought from a variety of informal sources about the symptoms and their possible origins. This proactive process allowed families to interpret the origin and severity of symptoms in terms of experiential knowledge.

"The warden, well she's bound to know about these things ... she looked at my arm and said 'Well, pet, it might be one of them mini strokes and if it is you'll just have to live with it till it passes off'. She's good and she knows her stuff for all not being trained or that. I didn't want to bother the Doctor anyway ... never had him out in all the years ..." (Margaret, interview 1, phase 1)

"I know I've been talking to two women who's mothers have had strokes." (Anne's daughter, interview 1, phase 1)

The process of information seeking did not necessarily reveal accurate or correct information; a large amount of health information in the media and on the internet is unregulated and therefore may not be correct. In addition, factually correct information was sometimes interpreted inappropriately.

"I'm on aspirin to water down the blood ... I read that you can bleed to death if you're blood's too thin ... drown in blood like, so what I do is instead of taking one aspirin every day, I take 3 aspirin at a time and then have a break to ... like, let it stop ... thinning and ... I might do the same when I get home again cos' they told me I bled in the brain so that proves it." (Thomas, interview 1, phase 1)

Following diagnosis, participants wanted as much technical and practical information as they could in order to understand what was happening to them. However, they expressed frustration that this information did little to assist them to make plans for the short and longer term future.

"But ... I know my Mam has had a stroke and they explain so much but they leave so much out ... and as I said to one of the nurses don't put it into long words, just explain it in simple terms what a stroke is. You know, I mean we don't want long words or nothing, just plain and simple, which I think a lot of people do so you know what you are dealing with." (Anne's daughter, interview 1, phase 1)

"They gave us some pamphlets on strokes, you know, and I was sitting reading a couple last night. As I said to my man... they're good but in some ways you're still sort of lost off with them, you know." (Susan's daughter, interview 1, phase 1)

In phase two, families described an element of denial in which there was a slow and painful realisation that a collection of minor symptoms and needs actually amounted to something serious.

"It was ... when we sat and watched that programme, me mam and me, all about cystic fibrosis. That was when in the pit of ... my tummy, I thought, that's my bairn. I cried, but after ... I felt like, well if they can go on and cope, so ... can we like." (Monica's mother, interview 2, phase 2)

The acceptance that something was seriously wrong was followed by a desire for as much information as possible that might answer questions about the origin and cause of symptoms. This was viewed as a reaction against the perceived lack of information given by service providers.

"*Even when they said it was cerebral palsy, they didn't tell you anything other than basically I was told I shouldn't have any more children.*" (Rebecca's mother, interview 2, phase 2)

Parents actively sought advice from friends and other parents, the media and literature (both popular and medical) about the possible causes and diagnoses of their child's symptoms in order to make sense of the unpredictable illness trajectory.

*"Well, it's funny but it was a couple of other kids that had the same condition as Jake. I talked to their mams and I had a funny feeling he was the same as them. Of course, the teachers thought I was paranoid or something. Anyway, I learned off them what Doctors to go to and they put me on to Dr *** and then Jake had to go into hospital and have the biopsy done and then they diagnosed it."* (Jake's mother, interview 1, phase 2)

"I said all along there was something the matter with her and all these parent books, Dr Spock and the like, it all made sense and I knew there was a little bit brain damage. There was a programme on telly that was about people with spina ... bifida and illnesses like that I thought, that's Becky. In the end I got a load of stuff from a very good Health Visitor and that proved it" (Rebecca's mother, interview 2, phase 1)

This information was gathered from a variety of sources including television programmes, books and magazines, and as a result parents were able to function emotionally in the belief that they were doing "*everything right*" (Toby's mother, interview 1, phase 2) for their child. This process alleviated some of the temporal uncertainty referred to earlier and was seen as a reaction against the perceived lack of information given by professionals concerning cause, diagnosis and prognosis of the chronic illness.

Despite the obvious need among families for accurate information about diagnosis and prognosis, both observation and questionnaire data suggested that for professional staff, concern over emotional and psychological well-being over-rode the importance given to information giving. Analysis of questionnaire data showed that staff from all disciplines would address concerns about prognosis with honesty only if asked a direct question and only if they felt the person was able to deal emotionally with a truthful answer about a poor prognosis. When asked about a stroke patient's likelihood of having a second stroke, most questionnaire respondents indicated that they would not directly answer the patient's questions about prognosis but would be positive about the patient's improvements and would defer control over this issue to the consultant physician or the nurses for further information. The majority of doctors and nurses in the survey indicated that they would tell the patient that he/she may have a further stroke (some indicated a 1 in 10 risk) and would discuss the reduction of risk factors with the patient. They would also tell the patient that most stroke victims do make some improvement. The only exception to this was a Speech and Language Therapist who stated that,

"I would tell the patient that she might have another stroke. Also encourage her to be positive about her strengths." (Speech therapist 5, questionnaire, phase 1)

In contrast to this, some respondents felt that it would be better to protect the patient from information about their prognosis. One Staff Nurse stated that,

"If her (the patient) family don't want her to know we should not tell her even if we don't agree with their policy." (Staff nurse 3, questionnaire, phase 1)

A Consultant working in elderly medicine stated he would answer questions about prognosis,

"*Guardedly! If asked a direct question – 1 in 10 risk of further stroke, unknown but high risk of impairment or death.*" (Consultant 1, questionnaire, phase 1)

In phase two, questionnaire respondents indicated that information giving about prognosis and the future course of the illness was the responsibility of the Consultant Paediatrician. Those Paediatricians who completed the questionnaire did identify this as being within their remit. However, in each phase, formal carers placed greater importance on information gathering, rather than in giving out information. It seemed that formal carers used information about the chronically ill person in order to make predictions about future prognosis in terms of recovery and rehabilitation, but often felt unable to share this with participants if the predictions were unfavourable. This was particularly the case when dealing with children with life-limiting illnesses.

"*We try to be positive, we know the boys aren't going to grow into men but you can't just do nothing. You can't say to parents, well, they're gonna die so what's the point?*" (Physiotherapist 2, observation period Peter 4, phase 2)

This frustration with the perceived lack of information given by professionals was actively addressed by Billy's mother. Billy's genetic illness is so rare that, despite the best efforts of Billy's mother, she could not find any other child in the region with the diagnosis, neither could she identify any member of staff who had even heard of the diagnostic category. She therefore travelled to America to meet an

American Consultant with a special research interest into this disorder and now keeps up regular correspondence with him.

H: "I'm trying to understand why it was important for you to meet the doctor you mentioned earlier. Would you explain it for me?"
I:"Well like I say, there's only one doctor. He's done all the research for the past 20 years and we keep in contact. He's told me what the outcome will be so I know what I'm expecting. All you can do is carry on."
H: " So the important thing was information about the future?"
*I: "Yes, but as well .. I mean when I fell for Daisy (*younger daughter*) they said I shouldn't have no more kids and then I fell for Daisy so ..and then I got this stroppy Doctor what come in one day and said, you know .. he didn't ask me.. he told the nurse to put me down for an abortion. I was so mad 'cos he didn't even know anything about the condition and – I even had to spell it for his bloody notes and how dare he judge .. my boy like that."*

This process of information gathering allowed her to accept the uncertainty of the illness trajectory and any subsequent deterioration. It also gave her access to information that was based on an accurate understanding of the illness and how it affected her son, rather than assumptions about poor quality of life based on prejudice and discrimination.

Overall, the information needs of patients and families seemed to be wholly at odds with the need of professionals to gather, rather than give information. The resulting frustration with the perceived lack of information about prognosis in terms both of technical, medical knowledge, and of coping and therapeutic techniques led to movement towards a process in which information was sought and interpreted from a variety of sources. This made the process of interfacing with formal carers more predictable and allowed participants to deal with unpredictable needs with some confidence.

3. Interpreting special events

A growing feeling emerged of frustration with the apparent inability of technical knowledge to assist in making predictions about the future or in locating oneself on the illness trajectory in terms of present or future needs and problems. This perceived deficit was addressed by interpreting the meaning behind organisational events and routines and relating these to their own illness. This allowed participants to make sense of the uncertainty surrounding their experiences of the interface with professional groups.

In phase one, this interpretation process began with observation data that showed an identifiable daily ward routine, characterised by recurrent events such as meals, medication regimes, Consultant ward visits. These events included daily contributions from nurses and physiotherapist and from ancillary staff such as domestics and porters. In addition to this emergent daily pattern, the contributions made by certain groups of staff often changed in nature and in time length throughout the patient's hospital stay. In interviews with patients and carers, it became clear that these changing contributions were interpreted as "*special events*" (Thomas, observation period 6, phase 1) that were given meaning by participants in relation to recovery and proximity to discharge from hospital. These events were unpredictable and uncertain in terms of both the time they occurred and the purpose and interactions that occurred during them. Events were given meaning and significance by the patients and their family in terms of gaining a picture of their past, present and future progress.

"Now she's (Mother) got to go to rehab and as far as I can gather, that's a good sign." (Anne's daughter, interview 1, phase 1)

"The nurse said the social worker had been to see Joe and I think it's a hint ... you know ... that Joe might not get home." (Joseph's daughter, interview 1, phase 1)

*"They want to take her downstairs (*to the physio gym*) so she must be improving a bit you see."* (Anne's daughter, interview 2, phase 1)

An example of this is when Susan was observed being taken down to the Occupational Therapy department for a functional assessment. As the porter wheeled her away, she remarked to a neighbouring patient;

"*Bring out the flags, I'll not be here this time tomorrow, I'll be going home. (laughter).*"
During her first interview, I invited the patient to reflect on this. She replied:

"So I'm only hoping and praying now, I mean I go home Monday for another assessment, I had a one yesterday which was very good, yes. I opened a tin of beans and put the kettle on and done a bit of toast and ... I don't think I spilt any on the bench ... you know by looking at other people like, when them therapy girls come for you ... you are on the road like. They don't say as much but you know."

Special events were interpreted as having positive implications for recovery and allowed participants to track one's position in the illness trajectory. However they were construed, they served to provide patients and carers with important clues about their progress, thus enabling them to cope with the lack of certainty and prognostic limits surrounding stroke rehabilitation.

Similarly, in phase two, parents referred to hospital admission and decisions that were taken regarding surgical or medical interventions for their child as indicators of where along a continuum of physical severity or psychological and educational progress their child was. For example, after a certain point in the illness

trajectory, children with Duchenne muscular dystrophy suffer from distortion of the spine, which affects respiratory function. This requires surgical intervention in the form of rods being placed in the spinal region, a procedure that can confer several good quality years of life for children with this severely life-limiting condition whose life expectancy is currently in the early twenties (Muscular Dystrophy Campaign, 2002). For parents of children who had undergone this procedure (n=2) or were contemplating the procedure (n=1), this represented "*the end of the road*" (Peter's father, interview 1, phase 2) as far as surgical intervention went for their child. Accepting the necessity of the procedure meant far more than weighing up the surgical pros and cons; it meant accepting that there was no cure for their son and that there was nothing more could medically be done for their son following this procedure, who could expect to gradually but steadily decline until an early death. Parents reported that this was not discussed with staff but was internalised and only spoken about as a result of the interview process.

> *"Just when we go through for his annual review. At the last one they said it was coming up time for the surgery that all the boys get eventually. You know, the rod in the back, like. They were all positive and oh it'll be good but they don't think what it means to us .. that your son is getting worse and coming towards ..."* (Jake's father, interview 1, phase 1)

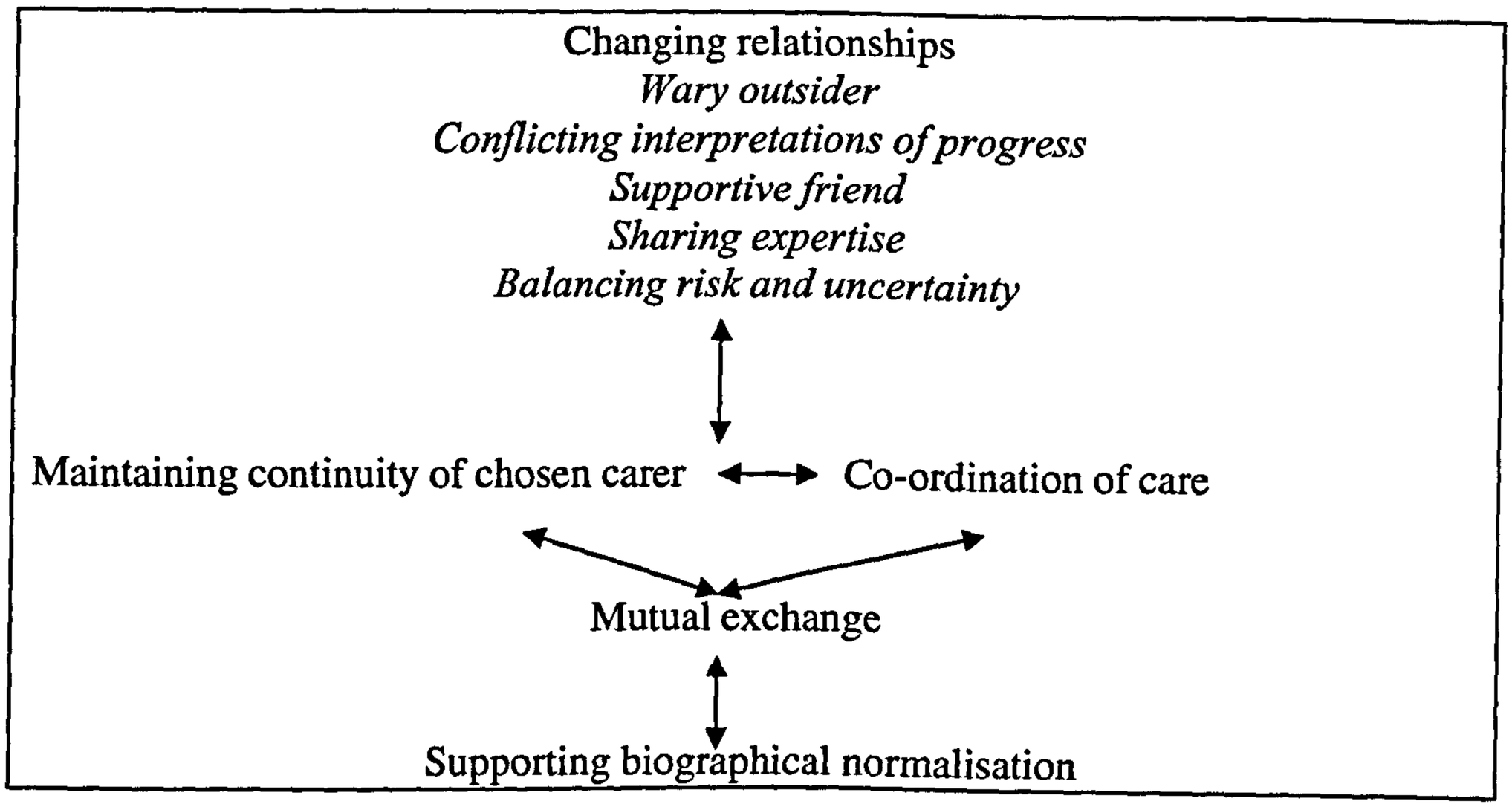
The interpretations and meanings given to medical and technical information seemed to allow participants to make decisions in the face of otherwise crippling uncertainty. The information management process seemed to reduce uncertainty by allowing participants to balance the likelihood of an event such as early death occurring or not occurring. By discounting or ignoring negative information, it was possible to

conclude that an event would or would not occur. It seems that the process of managing information conferred some control over acute episodes and conflicting needs referred to earlier. In addition, it allowed participants to manage their temporal uncertainty located within the past, present and future regarding their illness journey. It seemed that special events were usually interpreted in positive ways in order to make sense of uncertainty. However, another aspect of this sense making process was to actively maintain uncertainty by discounting or avoiding negative information. For example, in phase two, those children who *did* compare negatively with those around them in terms of physical or medical progress were thought to have done so because of some extraneous factor. By becoming aware of information and experiential knowledge, the families felt empowered to avoid this happening to them. This gave hope and allowed them to feel in control of their situation. For example, Monica's mum had been very upset by the death of a child who shared a diagnosis of cystic fibrosis with Monica and had been much fitter than Monica before she died. Monica's mum overcame her concern for her own child by speaking to other parents at the hospital who mutually agreed that the little girl had died due to negligence on the part of one of the hospital consultants. Monica's mum then made sure that her daughter was not, and would not be under the care of that particular consultant. In this way, gathering and interpreting (either accurately or not) information allowed her to feel in control of the unpredictable needs and uncertain future of her child.

Summary of the process of accepting uncertainty

The strategy of information management is presented in this chapter as a proactive process that begins with frustration at the perceived lack of certain, definitive information about the cause, diagnosis, and prognosis of the child or adult's chronic illness. This sense making process then leads to the interpretation of experiential and technical knowledge drawn from an awareness of organisational routines and special events. Far from being solely about gathering as much information as possible, this process was about sorting through this information and discounting or avoiding negative information. In this way uncertainty was either reduced, or increased, according to the needs of the family at any particular time. Via this process, participants began to accept the uncertainty inherent in the illness trajectory.

The Process of Adapting to Uncertainty



The final section in this chapter outlines the process of adapting to uncertainty in the context of the interface between the relationship triad. Once understanding and acceptance of the continuing presence of uncertainty along the illness trajectory had been reached, participants demonstrated strategies that allowed that to adapt to the continued uncertainty in their lives. These strategies only came into play once participants had moved from viewing professional staff as 'wary outsiders' to 'supportive friends'. This relationship continuum is discussed next and is followed by a discussion of the ways in which participants maintained continuity and co-ordination of care with chosen carers.

1. Wary outsider

At every stage of the illness trajectory, patients and carers felt that members of staff, in particular nurses and doctors, were party to information, knowledge and opinions about the patient's future progress that they were not. Similarly, parents often expressed the belief that information held by professional staff was not shared with them concerning prognostic goals. It was felt by participants that this information was either directly withheld or was presented in a general, indirect way that did not tell them what they wanted to know.

"You think well, do they know? Because when it first happened and I asked one of the nurses, they said oh, you have an idea between 6 and 7 weeks how things are going to go, you know." (Matthew's wife, interview 2, phase 1)

"I know there's no time limit on it but I think staff must sort of know up to a certain extent about how things are going to go." (Catherine, interview 1, phase 1)

"Well, being a nurse, you'll know how elusive they are about things like this but .. I said all along there was something the matter but the Doctor wouldn't have it." (Rebecca's mother, interview 2, phase 2)

Particularly at the peri-diagnostic stage of the trajectory, this perceived with-holding of information caused carers to feel that no-one cared and that all the responsibility was on their shoulders.

"As I said and ... I'm not a person who, to be honest, who can talk to anybody, you know, because I mean I haven't got a sister, you know and you sort of feel responsible plus ... maybe if you had someone to talk to about things like a sister, you might feel a bit better or if you had somebody standing saying I'll come with you to see so-and-so but there's not that, you know, it's just sort of left on to you". (Anne's daughter, interview 2, phase 1)

These feelings of isolation seemed to be compounded by the perception held by some participants that they were in receipt of services delivered by over-stressed, under-

resourced staff who had little time to give individualised care and were therefore "*outsiders*" (Sam's mother, interview 1, phase 2) to the family unit.

"I hate resi (residential unit). *It was hell. I had to make the bed in front of her .. Sheila* (residential teacher). *Like the bairns .. I'm 15 but she treats me like a bairn. She's an old witch."* (Simon, interview 2, phase 2)

In phase one, this frustration at a perceived lack of individualised care was expressed in relation to the boredom experienced while being subject to a hospital routine that involved little contact with staff for large segments of the day, interspersed with short periods of high activity. For example, throughout a two-hour period of observation during the peri-diagnostic period, Matthew was seen to come into direct verbal and physical contact with 26 different staff from 10 different professional and ancillary groups. Following diagnosis, a three-hour period of observation recorded no interactions between Matthew and any member of staff or volunteers on the ward. His isolation was broken only when two nurses came to give him a positional change. This was reflected in other qualitative analysis of daily experiences of other patients. Following diagnosis, participants spent a lot of time without any verbal, physical, or even simply eye contact interactions from staff. This was particularly true of weekends and evenings. This study was not a quantitative study, with random sampling time units of observation of staff- patient interactions. Therefore, these findings may not have reflected the reality of patient experiences. However, interview data bore out observational data indicating the level of boredom experienced by patients during their stay, most particularly, after a diagnosis had been established.

Feelings of boredom, leading to feelings of uselessness, social isolation and increased levels of uncertainty were expressed with increasing frequency throughout the hospital stay as the patient's physical condition improved.

"I mean the programme during the day isn't that ... certainly not stimulating and I think I withdrew to a certain extent and I was just ... I felt like I was just a moron, just sort of sat there and all you could do was think." (Catherine, interview 3, phase 1)

This led to discussions about the mutual low priority given to emotional needs. Patients felt that their emotional and psychological needs were a very low priority in the busy wards.

"I spent an awful lot of time on my own. Nurses did come in and they did chat but obviously they have a busy workload and they can't spend a lot of time sitting. They would get into trouble for one thing if they came and sat and talked to you so I was very bored but I found it very difficult to do anything about it." (Joseph, interview 1, phase 1)

2. Conflicting interpretations of progress

Staff were very clear about the therapeutic necessity for remaining in hospital following diagnosis. However, this was perceived to be at odds with the patient's experience of isolation and boredom. During informal conversations with staff, it emerged that staffs' views about patient progress were often quite different from the views of patients. It seems that patients and their carers made assumptions about the acute management relating to the likelihood of a cure. When no cure materialised, powerlessness and disappointment were experienced. Stroke patients were given 'rehabilitation' to facilitate 'stroke recovery' but little discussion was made about the

levels of recovery that were actually achievable. Conflicting interpretations of progress then confused and hindered the person from adapting to uncertainty.

In addition, it appeared that perceived lack of continuity of care compounded conflicting interpretations of progress. For example, an improvement in leg muscle tone was received with great encouragement and praise by a staff member who had perhaps not dealt with the patient before. The patient however, would see this as an unimportant, trivial incident since the improvement would not lead to discharge from hospital and would certainly not restore the patient back to his previous physical state. The conflict was attributed by the patient to the staff member's lack of knowledge about him/her.

"This morning I was having a sort of a leg moving exercise. They said I'm doing well but if I could do half a dozen steps it would be grand. I felt as though I'd failed but they didn't see it that way. They'd not seen me anyway since it happened so how do they know what's good and what's not" (Andrew, interview 2, phase 1)

It seemed that the lack of certainty or information about the patient's progress gave little incentive for physical rehabilitation and instead, patient's often put their efforts into getting home as quickly as possible.

"The physio said they would try and get me back as close as normal, sort of what I was before, but there wasn't a guarantee that it would be 100%. So I thought right, well, I'll just work to get discharged by the weekend. My usual one was one holiday you see." (Catherine, interview 2, phase 1)

In the special school phase, both therapies and education was seen to be very much focused on present achievements and short-term goals. Long-term goals in relation to future plans for the child were rarely discussed, either in educational terms or in terms of physical or social progress. Questionnaire data suggested a

reluctance among formal carers to plan for the future because physical and social needs were perceived to fluctuate so much that interventions could only be focused on present needs and problems. This was seen to add to uncertainty experienced by participants and underlined their own need to accept that their illness would affect them in the long-term, even though the precise details of this remained uncertain.

"*I wanted her out of there* (Smithson School) *and into a normal school. Not necessarily now but in the future. But at the end of the day we went through it and they said just take one day at a time, you know. We don't know what she'll be like in a year or three years. We just know she's always have problems. So .. you've just got to accept it.*" (Isabel's mother, interview 1, phase 2)

3. Temporal conflict

A tension emerged from the data between participants wanting to plan for the future in order to create some certainty around chronicity, while formal carers were reluctant to commit to any long-term plans without further information. This tension was expressed by formal carers as a desire for a "*crystal ball*" (Staff nurse, observation, phase 1), in that families wanted concrete information about the future that it simply was not possible to give. Formal carers were reluctant to acknowledge that the only certainty in the illness trajectory lay in the fact that the illness would continue to have an, albeit indefinable, long-term chronic effect on the life of the patient and family. The complex tension created by the paradox of certainty of chronicity within an overall experience of uncertainty led to a situation in which participants often expressed worries and fears in relation to past and future worries about the chronic illness but were often keen to be seen to be coping in the present

moment. This contrasted with the fact that interventions by formal carers were focused firmly on gathering information in the here-and-now.

"My aims would focus on full medical clerk and information gathering about problems now." (Consultant 2, questionnaire phase 1)

When asked about long-term aims in the questionnaire, formal carers were only prepared to make very tentative comments with the proviso of gathering more information that could only be carried out at the time of the intervention. Participants often expressed the feeling that technical or medical information that *was* given to them by nurses and therapists would be impractical in the "*real world*" (Thomas, interview 2, phase 1). The amount that this was perceived to be taken on board by staff was extremely important in motivation and building good relationships.

"At the moment we are looking at my technique of walking and where it's going wrong. When I have to put weight on to the leg that's affected, it obviously is a bit of a strain and so you do it the easiest way by leaving all your weight over onto one side, onto the left. The physiotherapist said at least I know where I'm going wrong and it can be put right. She said I know you've got to get around at home and ... it would be wrong of me to say don't walk on your own because you're doing it wrong so ...that gave me a lot of motivation because I know she understands." (Catherine, interview 3, phase 1)

This sense of having a supportive alliance with a particular member of staff seemed to allow participants to begin to adapt to the uncertainty of their lives. Participants appeared to combat boredom and social isolation by enlisting members of staff who they knew they could rely on for support and even just a friendly wave. Boredom and social isolation was not a feature of representations of the experiences of children and their families. However, they shared with families in phase one a pattern of goal oriented interactions intended to elicit both information and support from

professional staff. This involved identifying, befriending, and maintaining a positive relationship with a member of staff who were seen to share a personal characteristic with the participant, such as age, gender, or place of origin as described in the following section.

4. Supportive friend

Participants often developed relationships with certain members of staff who they identified as being *"chatty"* (Lucy, phase 2), friendly, or particularly willing to offer support and information. These staff were addressed by the participants using first names and were almost always perceived to share a personal characteristic, such as similar age, class or gender, with the participant who had identified them.

"I think she (Physiotherapist) is enjoying doing physio with me because I'm young and ... she's young." (Catherine, interview 3, phase 1)

"The nurse came, she was lovely and very understanding and she became like a friend to me. The male nurses were okay. I have to say that or I'll get wrong. But they weren't the same " (Margaret, interview 1, phase 1)

*"I really like Paul. He's my physio. He's from Fenham where I live but he doesn't live there no more. No." (*Lucy, interview 1, phase 2)

"I think you tend to get your favourites. I'm sure everyone does. That may be wrong in some respects but, you know." (Billy's mother, interview 1, phase 2)

Those staff who were perceived as being markedly different from the participant in terms of age, class, or gender were sometimes regarded with suspicion and were seen as outsiders to the child or adult's world. For example, Simon talked about a photo of a group of staff and students having a summer picnic.

S. "We get health ed. together. We always argue together. There's the caretaker. We always bang on his door and run away (laughter). He tried to hit Alan once, him. He jumped over Mark's chair and grabbed him. Wish I could have reached over and hit him but I couldn't."
H. Why was that, do you think?
S. "*Cos he's git ould* (really old). *Mr Jones (*deputy head) *is canny. He's young and I get on really well with him. You can have a laugh."* (Simon, interview 2, phase 2)

Although the children did not appear to share the aim of gaining prognostic information from friendly staff, they shared with other participant groups the fact that the cultivation of these relationships led to emotional and social support in each phase. It seemed that in terms of managing the uncertain trajectory, perceived professional expertise was less important to participants than personal characteristics. For example;

"I can normally say whether I like someone straight off and I took to certain teachers at the school. Well, I wouldn't send Billy to any other school." (Billy's mother, interview 1, phase 2)

"I mean, all you need is somebody on your side and the female doctor came and sat and talked and she was wonderful." (Susan, interview 1, phase 1)

An important aspect of these supportive relationships was that they involved the sharing of expertise and a tacit acknowledgement of the certainty of chronicity, rather than a futile desire for an end to the uncertainty of the illness trajectory, between families and members of staff, as demonstrated in the following section.

5. Sharing expertise

Family members often reported that they had been invited to watch and take part in therapy with the child or adult, or in discussion meetings in the form of multi-professional case conferences or parent evenings. At first, the purpose of this

involvement seemed to be to show that the client was improving physically or educationally.

*"I got a phone call from **** to say did we want to come and watch. So we went to see the physiotherapy yesterday. That was great, it was such a morale booster for us because we've only seen him slumped in the chair. There, we saw him ... he had his feet over and you know saying reach over and touch my hand and we saw that and then we saw him standing. It was great."* (Joseph's wife, interview 1, phase 1)

It later became apparent that family members saw these episodes as a way of befriending members of staff and gaining a sense that decisions and experiential knowledge about care were shared rather than dictated by an uninterested outsider.

"I went there (school) *last week, that you know, to share the .. each of the children have chosen some subjects so we .. I went to see the head teacher and request him that both Hanif and myself are interested less in music than in one useful subject because if I go back to Bangladesh there is no future with music at all. I worried that his physical ability is more important than his education at this level but the head shared my view he is a brilliant child. Any education he can take."* (Hanif's father, interview 1, phase 2)

In phase one, in the context of these supportive relationships, patients and carers began to accept that definitive, concrete facts about stroke rehabilitation were limited and that most of the information they received was conjectural and was based on feelings and opinions. With an acceptance of this came a realisation that the emotional support given by people was more important than information in terms of dealing with the reality of uncertainty.

"But the staff haven't really got time to talk to you because of the pressure .. well, it's hard for them when they don't know the answers to your questions. I catch their eye ... they just say I've got to be patient and wait for him to recover in his own time." (Joseph's wife, interview 3, phase 1)

"I know it's just a matter of time but it's so hard, really frustrating, so when the nurses have got time, I sit and cry and cry ... to me that's what counts. I can't have answers ... but at least they sit and hold my hand." (Sally, interview 2, phase 1)

Similarly, in phase two, parents began to realise that definitive facts regarding their child's illness journey were non-existent and that supportive guidance was needed to assist them through this uncertainty. This realisation was made during a process of balancing physical risks against an ability to predict the illness journey. This is discussed in the following section.

6. Balancing risk and uncertainty

Within the context of an uncertain prognosis regarding biophysical and functional impairments, people with chronic illness and their families in each phase underwent a process of balancing their psychosocial needs with the needs of informal carers, the advice and expectations of formal carers, and their perceptions of risk to physical well-being. In both phases, participants described many occasions in which they themselves felt that psychosocial needs were more important, even if they placed themselves at risk of physical harm by doing so. This appeared to be the case from diagnosis onwards.

> *"We promised my friend that we'd have her children for the weekend, unknown to her, we'd promised her husband because it is her 40th birthday and he was going to take her away. I think we'll muddle through. I don't know what my friend will think when she finds out I self-discharged for the weekend though."* (Catherine, interview 2, phase 1)

In phase one, the fact that professional groups of staff expressed opinions and concerns about physical risk was balanced against the patient's desire to return home from hospital. Clients and their families were often given the option of nursing home

care following discharge from hospital in order to ensure the physical 'safety' and wellbeing of the patient.

*"The speech therapist lady came up and introduced herself and ... she said 'Have the physiotherapists said anything to you about not having *** home? ... I didn't want to hear that. I want him home. We've been together, we've been married 34 years, so I said 'Oh, no.' Maybe they were just ... because we'd been seeing the rehab nurse last Thursday and sort of dropped a hint and ... you know ... that *** might not get home ... but I'm ignoring it because I don't want to hear it"* (Joseph's wife, interview 2, phase 1)

This conflict between physical needs and psychological well-being seemed to involve a subtle balancing act between risk and uncertainty that was touched upon in questionnaire data. This balancing act seemed to be largely dependent on the assessment of nursing staff. Nurses were seen by the majority of professional groups (including their own) as having the final say in planning decisions about care that involved both the need to *"ensure independence"* while at the same time providing an assessment of *"emotional support, carer ability to cope and physical safety"* (Consultant Geriatrician, questionnaire, phase 1). Following discharge from hospital, this apparent 'competition' between physical and mental wellbeing expressed itself in terms of a *'juggling act'* (Catherine's husband, interview 1, phase 1) between ensuring physical safety and allowing a sense of personhood to emerge.

This juggling act was evidenced in the cases of several children in this study who actively rejected physiotherapy aids, equipment and therapy which enabled them to walk and instead opted to use a wheelchair.

"I used to like walking but when I come here I didn't. They used to make me wear these callies (leg callipers) *and they were awful. They used to hurt. So I just didn't want to walk no more. They wouldn't listen. I got my Mother up and then I stopped wearing them."*
"Wow. Tell me more about these callies. I don't know much about them."

"I just got sick of them. Plus you could .. I mean imagine someone like Peter .. imagine that chair flying around and they knocked you over. Crap. I don't like it. I don't know. Now there's 6 of us .. no 5 of us in wheelchairs and it's .. we just laugh and play hockey. You can't do that with stupid callies." (Simon, interview 2 phase 2, talking about a photo of himself sitting in his wheelchair)

For this boy and his family, personal safety and a feeling of fitting in with his peers were valued more highly than the advice from the physiotherapists about the physical benefits of walking. Staff described this juggling act in questionnaire data as a major tension in their work between acknowledging the wishes of the person against the fulfilment of their role requirements.

"Obviously both Kate and her parents need to be made aware of the detrimental effects using a wheelchair may have for Kate's bowel/ bladder/ kidneys etc. But once made fully aware then it should be a personal choice as long as the consequences are outlined." (Teacher 7, questionnaire, phase2)

Strategies used to adapt to uncertainty at the interface between the relationship triad

What emerges from this analysis is a picture of relationships that developed along a continuum of support and adaptation to uncertainty within the illness experience. It seems that the adult participants in this study initially viewed members of staff as uninterested outsiders to their family unit with no time, resources or inclination to deliver care in a way that was responsive to the biographical aspects of the person's illness journey. This aspect of findings did not emerge from data taken from the children, although they did share some qualitative evidence of favouring staff whose age, gender, or place of origin was similar to their own biographical characteristics. Several factors emerged from data with all participants in each phase that influenced the way in which the interface triad was represented within the experience of uncertainty. These factors depended on the model of care adopted within the organisational context of care or education and the ways in which conflict between families and professional staff was recognised and resolved via a process of balancing risks to health and physical well being and uncertainty about the illness course. These changing, unpredictable factors were managed using a variety of strategies intended to maintain positive, continuous relationships with identified members of staff throughout the illness trajectory. Continuity of carer allowed responsibility for co-ordination of care to be negotiated in a fluid reflexive way that is discussed below in relation to ensuring that all members of the relationship triad benefited in some way from the care-giving/ care-receipt relationship. This complex,

dynamic set of strategies allowed participants to negotiate their trajectories and incorporate their biographies into an uncertain and unpredictable illness journey.

1. Maintaining continuity of carer

Informal discussions during the observation phase indicated the importance placed by staff at the special school concerning communication between staff and family members. Staff members told me that they valued the information they got from parents about the emotional, physical, and educational progress of the children, and more-over, recognised that parents valued the two-way sharing of experiential knowledge about their child. Without exception, parents were able to identify at least one staff member who they relied on for information about the progress of their child.

"I mean I really like ******** *(*physiotherapist*), yeah. I mean she's not just the physio, she becomes your friend as well."*
(Billy's mother, interview 1, phase 2)

In particular, it seemed that being able to rely on a supportive member of staff reduced uncertainty about needs and the ways in which those needs might be met. For example;

"**** *(*the residential unit teacher*)rings me if there's anything at all which means I don't worry in between 'cos I know she'd tell me if there was anything. Like the other week she rang and said she was having a bit of trouble with one of the girls in resi causing trouble with Lucy, running off and leaving her like in her chair. Lucy hadn't said a word but I knew there was something up."* (Lucy's mother, interview 2, phase 2)

Whether physical, emotional or educational progress was given precedence depended on the needs of the child and this in turn influenced the professional group of the

relevant member of staff. For example, in the case of Debbie, this little girl was progressing as expected educationally and emotionally. During an informal discussion with them, her parents expressed uncertainty about the physical improvements she might make and they therefore invested a lot of emotional energy into the relationship with the physiotherapists. This sentiment was mirrored by Liam's carers;

"The physio ... not so much the teachers but the physio, we have a lot to do with her. We're always on the phone to her. She's smashing and she keeps us in touch with what is happening. It's important because we have to carry on where she leaves off so we have to know about any changes to the exercises and so on but she really goes out of her way to call all the time and she doesn't mind us calling her." (Liam's father, interview 1, phase 2)

The children themselves often had a favourite staff member who they would approach if they were experiencing any emotional, social or educational difficulties. This was facilitated by the low staff-turnover and the relatively small staff numbers within the school, meaning that children got to know the staff quickly and were able to identify a particularly supportive staff member early in their school career.

*"I really like Mr ****. He's the art teacher. Well I like art and I was saying to him how I missed my piano lessons now I'm in resi every week and so he arranged for me to have some here. He's really good."* (Liam, interview 1, phase 2)

In addition, many of the children were regularly admitted to hospital and could identify a favourite member of ward staff.

"I know all the nurses because I go on ward 19 all the time. Especially Michelle. Do you know her?"
"No, tell me about her!"
"Well, when I'm sick I go to the ward and she runs up and give me kisses and hugs and I don't mind leaving my Mam then." (Kate, interview 1, phase 2)

In phase one, patients and their families often felt that hospital intervention had *"saved my life"* (Anne, interview 1, phase 1). This, in part, contributed to a relationship framework with service providers whereby the patient felt very grateful to staff and developed a confidence in them that endured long after discharge from hospital. In other words, even though the care environment and its occupants was recognised as unpredictable and uncertain, confidence in the high standard of care conferred a level of stability and predictability over the situation. As a result of the gratitude expressed, patients sometimes minimised the importance of their needs. This appeared to confer some level of control and predictability over subsequent interactions with service providers and began the process of identifying and maintaining a relationship with a favourite member of staff.

'Well, you know, they brought me back to life so I don't like to bother them with trivial things. They work so hard.' (Sally, interview 1, phase 1).

In addition to this, patients and their families often gave emotional and psychological well-being a low priority and felt that any questions they had would add to the heavy workload of the staff.

"Everyone has such a busy schedule that you feel awful taking up the time so you would possibly not bother." (Sally, interview 2, phase 1)

Keeping in touch with one particular carer seemed to assist participants in making sense of their illness biography in terms of tying in past and present events with future events.

"The Muscular Dystrophy family officer I was saying about. She's done loads for us over the years .. all the red tape and all the rest of it, you know? And she's organising this trip to Disney Land, well, Jake's going. She did a one when he was about 6 or something as well." (Jake's mother, interview 1, phase 1)

It also allowed for a consensus to be reached regarding the occasional conflict of needs by asking the chosen formal carer to act as a negotiator.

"I find that such as like speech therapy, you know, you think to yourself, you know, she's been the main one for us and when we needed to see the Doctor to get this argument about discharge out the way, she organised it all and sat there and wrote it all down for us like." (Ina, interview 1, phase 1)

It seems that proactively maintaining a relationship with one particular carer allowed participants to negotiate the interface throughout their illness trajectory with some feeling of control and influence over events. This shared history assisted them to come to some acceptance of the chronicity inherent in their illness and allowed them to embark upon normalising strategies that went some way to reducing the unpredictable family lives they were experiencing. Patients spoke in terms of trust when they spoke about a good relationship with a particular member of staff. One aspect of this was a feeling that the staff member was competent and committed to their job.

*"I always felt that I was better with Sally (*physiotherapist*) than I was say at home with my husband because I didn't trust him in the same way that he wouldn't let something happen. I mean, he wouldn't let something happen to me on purpose but I didn't feel he was able to cope in the same way. Sally knew exactly how to handle me and ... I really do feel at ease with her and I think, you know, they're ... it's not just a job to them. It matters to them and they put every effort into it.* (Catherine, interview 4, phase 1)

The role of staff members in creating and maintaining these relationships was not always clear but seemed to occur organically as a result of chance and indefinable personal characteristics. However, observation data indicated that staff were often proactive in initiating supportive therapeutic relationships in order to

resolve conflict and offer continuity. This is demonstrated in the observation memo below.

Observation period 6 with Anne
Following a period of one hour in which several members of staff entered the bay but did not make eye contact or verbal contact with Anne, a social worker and two physiotherapists came into the bay and explained to Anne that they needed to assess her mobility in order to make plans for discharge from hospital. Anne is still unable to speak but nods as they talk. During the assessment, the social worker comments on the "challenging" behaviour of Anne's daughter when interacting with staff. Everyone laughs, including Anne. The social worker asks whether either of the physiotherapists have been able to build a positive relationship with Anne's daughter. They each reply that they have tried but that their attempts have been met with aggressive hostility, which they attribute to the fact that she loves her mother and wants the best for her. They suggest that the speech therapist has been more successful in having open dialogue with Anne's daughter about future plans; to this Anne nods vigorously. The social worker suggests that she should ask the speech therapist to attend any future meetings with Anne's daughter. She asks Anne if she agrees to this. Anne again nods vigorously.

During informal discussions, it emerged that negotiations about sharing care, taking responsibility for co-ordinating care, and giving continuity, seemed to occur on an ad hoc, individual basis that was entirely reactive to the needs/personalities of family members and located within the staffing/resource context at any given time. In particular, it seemed that even though patients and children had 'named' members of staff from a variety of disciplines, for example, a named nurse or a named physiotherapist, if that member of staff went on annual leave or sick leave, another member of staff would quickly bridge the gap using the processes described above.

It seems that in each phase, continuity of carer mediated uncertainty on several levels; firstly it conferred a level of control over acute episodes in which participants were admitted to hospital. The fact of a familiar face made the environment feel less uncertain but also, a shared history with a formal carer

overcame some of the tension alluded to earlier in terms of firstly keeping family life private, and secondly, allowed for carers to make judgements about current needs based on past knowledge of the family. Questionnaire data supports this finding in the sense that formal carers often reported that they could not fully answer questions without "*getting to know the patient and the family.*" (Staff nurse 3, questionnaire, phase 1). Adaptation to uncertainty was seen to be intrinsically bound to the interface with identified formal carers in the sense that continuity of care was important for maintaining consistency and predictability within the biography of the chronically ill person. For example, when relating the biography of a child to me, parents would bring up the same names of certain staff members time and again. Analysis of questionnaire data showed that continuity of care was highlighted in relation to co-ordination of care by professional members of staff and is therefore discussed next in relation to ways in which effective co-ordination of care mediated uncertainty across the illness trajectory.

2. Co-ordination of care

Analysis of questionnaire data found that the majority of respondents shared a variety of training and experiential backgrounds, particularly in the case of special school staff. For example, one respondent was employed as a medical/ pastoral worker in a special school but had formal training and experience as both a nurse and as a teacher. Perhaps this variety of training contributed to the wide understanding of each other's role shown in the analysis. This is evidenced by the correlation between what, for example, a social worker said they themselves would do and what other

respondents said a social worker might do in relation to the case studies. Respondents from all professional groups indicated that they would work closely in partnership with the client and family and would see themselves as being *'advocates'* (Teacher 4, questionnaire, phase 2) in the sense of making sure that the child's or patient's wishes were taken into account in any decision-making.

In each phase, favourite or chosen members of staff took responsibility for co-ordinating the multi-professional care of the child or adult, regardless of professional group or grade. Questionnaire data was therefore analysed with co-ordination of care in mind. The questionnaire in each phase asked respondents to identify their own and other groups' immediate and long term aims for each patient or child outlined in the case studies (see appendix 8.2 and 8.3). Respondents from each professional group clearly identified their long term aims which were predominantly concerned with physical and medical needs, framed within a discourse of recovery and rehabilitation.

"To ensure eating a safe diet or being fed by gastrostomy of this were not possible." (Speech and language therapist 2, questionnaire, phase 1)

"Manage transfer needs in all situation, either independently or with a team of carers." (Occupational therapist 1, questionnaire, phase 2)

In phase one, regardless of their professional group, without exception, every respondent identified contributions concerning emotional or psychological problems as the role of someone other than themselves. The majority of respondents (n=28) stated this issue should be taken up by the nursing staff who should then refer to psychologists if concerns were identified.

The only exception to this in phase two was seen in responses from teachers who were focused on the behavioural and socio-sexual issues that were identified within two of the case studies in phase two questionnaire. For the teachers, aims of care typically included;

" Reward him for good behaviour either verbally or giving him a treat." (Teacher 4, questionnaire, phase 2)

Qualitative comparisons of responses from different professional groups showed that different groups of staff often identified similar aims. For example in phase one, Speech and Language Therapists, Occupational Therapists, and Staff Nurses all stated that their immediate aims would include an assessment of speech and swallowing. This type of overlap was common to most of the identified aims which ranged from maintenance of a clear chest to confirmation of a feasible discharge. Long term aims ranged from the management of elimination needs to the provision for additional home care. Interestingly, only Speech and Language Therapists identified the long term aim of educating and emotionally supporting the patient and family. Hospital based professional aims were geared towards getting the patient and family through the system in as short a time as possible in order to achieve a timely discharge from hospital. This was reflected in findings from phase two in which respondents seemed to focus largely on physical, behavioural and developmental aims that were focused on assisting the child to 'fit' into the context of care. For example, behavioural difficulties were addressed in order that the child could fit into the classroom context.

"To establish a behaviour modification programme amongst all involved staff avoiding the use of physical restraint or intervention or only if absolutely necessary, to ensure safety of pupils." (Teacher 2, questionnaire, phase 2)

When asked to outline what contribution different groups of staff would make to the care and treatment of a stroke patient, most respondents outlined fairly superficial contributions such as a Physiotherapist would be required to *"improve mobility and transfers" (*Physiotherapist 2, questionnaire, phase 1*)*. These correlated well with the contributions each group identified that they themselves would make. Questionnaire case-studies incorporated multiple pathology and although formal carers may have been influenced by this issue in their clinical decisions, this was not evident in the questionnaire data. In phase one, observation data bears out that unless multiple pathology had a direct bearing on stroke recovery, formal carers did not discuss this with patients or families. Similarly, in phase two, multiple pathology was not directly referred to as an issue, although formal carers stated a holistic approach to the needs of the child was very important. In all cases, respondents attributed responsibility for overall care and co-ordination of needs and services to the Consultant physician in phase one, or the Consultant Paediatrician in phase two. However, those consultants who completed the questionnaires did not identify these areas as being an aspect of their own role. This suggests that formal carers may assume that a colleague is carrying out the task of co-ordinating the complex care of a chronically ill person, when in fact, responsibility rests firmly with the person and their family.

In several cases, the perceived lack of recognition of this responsibility means that participants were left with a feeling of "*working blind*" (Thomas, interview 3, phase 1). This then heightened uncertainty about both the process and outcome of decisions regarding care. However, more typically, this data contrasts with interview and observational data that pointed to the development of supportive, reflexive relationships based on mutual positive regard for personal aspects within the personalities of each member of the interface triad. Within this triad, responsibility for co-ordination of care was shared and the member of staff who chose, or was chosen to be part of that triad, was there as a result of personal characteristics, rather than rank or medical qualifications.

It is possible to suggest that questionnaire analysis contrasts with other data due to the methodological issues concerned with the design and completion of the questionnaires, in which respondents answered questions in a cold way that was divorced from the realities of actual care delivery. However, it also seems likely that the questionnaire data identified a very real tension in the work of members of staff who have a rational and professional duty to address needs in relation to current provision and resources, against their emotional ability to respond reflexively to the need for supportive, compassionate relationships that relied on '*going that bit further'* (Social worker, observation with Lucy, phase 2) for a family, a patient or a child. This reflexive relationship is further discussed in the following section.

3. Mutual exchange

Mutual exchange is discussed in this section as a coping strategy in which all parties within the care-giving/care-receipt triad benefited from the relationship between a chosen professional carer, the chronically ill person and carer. This strategy was first identified as a '*trade off*' between patients and their formal carers in phase one and the development of my understanding about this strategy is outlined here.

The code '*trade off*' emerged during the analysis of the first interview, with Catherine, carried out in phase one. This was used as a label for segments of data in which Catherine described how she pushed herself to achieve certain physical milestones and negotiated with staff to allow for an early discharge from hospital, even though social services care and aids and equipment were not yet in place. Analysis resulted in the code '*trade-off*' being grouped together with '*progress*'. '*physical milestones*', and '*goal settings*' under the category 'restoration', which comprised all the segments of data about the physical, emotional, social and relationship goals that were set during the first phase of the illness experience.

During subsequent interviews with Catherine and with each of the other interview participants, I explored ways in which they used 'trade-offs' in order to understand the code more fully. For example, in the next interview with Catherine, a property of the code was revealed as the feeling of control that trade-off gave to her over the processes and relationships she encountered. This revealed that Catherine saw herself as an active participant of her care over which she was able to exert some control. Other participants demonstrated this sense of agency. For example;

"You have to keep in with the docs. You have to pretend you know nowt when really, I've looked after her all these weeks and not a problem but I suppose they are just doing their job.' (Ina's husband, interview 1, phase1)

Several codes emerged that shared properties with this code such as *'manipulation'* in terms of the feeling of control and certainty conferred to the person using them. Teasing out the similarities and differences between these codes became a means of identifying properties and dimensions of the code and how it might relate to other categories. As data collection and analysis progressed, a stage was reached where no new properties or relationships began to emerge the code was theoretically saturated. At this stage, I renamed 'trade-off' as 'mutual exchange' to reflect the dynamic process between two parties who each benefit from an action or process. For example, Catherine received physical care from her husband and 9 year old daughter.

"They will do things for me and ... look after me. They're coming home on the school bus now so I suppose they are more independent than they were because I took them everywhere. Somehow I feel that my daughter is as much a mother now for me as I am for her in a funny way." (Catherine, interview 3, phase 1)

In return, she gave emotional and practical support and guidance in caring for their two children. At this stage, *'mutual exchange'* became a category with several sub-categories – control over unpredictable needs, shared care, role negotiation, patient-carer relationships. Mutual exchange was typically evidenced during rehabilitation in which people felt that they ought to put as much effort in themselves to their therapy as their physiotherapist. Continuity of carer seemed to have a positive effect on motivation to improve physically. This effect seemed to have an element of reciprocity in that participants felt they owed something to their chosen member of staff.

"Certainly I think they put the care of the patient first and they are really committed and ... I mean I want to do my best for her (staff nurse) *as much as myself."* (Sally, interview 1, phase 1)

This reciprocity was also expressed as a desire to assist the formal carer in some small way. Patients and their families often took it upon themselves to assist staff members in a caring role, either towards the client or another hospital patient. For example, Matthew's wife has experience of working with elderly people and told me,

"When they're busy with Matthew, you know, they draw the curtains. I go and sit with the man in the opposite bed because he's a terror for wanting to get out of the hospital, you know. So I try to keep him occupied while the nurses are busy with their treatment and I try to help him the best I can and at night I make sure his buzzer's near him because he panics about that. They all start shouting together and the nurses don't know which way to run." (Matthew's wife, interview 1, phase 1)

In each instance of identifying a relationship with a specific member of staff, participants asserted their proactive role and sense of agency in maintaining that relationship. It emerged, from observation data, that each member of staff recognised and asserted a similar level of influence in the maintenance of this dynamic process. In other words, they felt able to choose to remain involved in a supportive relationship, or to withdraw and to enlist the help of another member of staff, particularly in situations where conflict arose. For instance, Billy's mother commented at length about the emotional support she had received from a physiotherapist based at her son's school and her frustration that her son was no longer allocated this member of staff.

*"You just get used to one and then they decide to change to another physio. I really liked ******. I haven't managed to make that relationship with the one prior or the one I've got now. With ****** I knew that I could ring up any time. It may not have had nothing to do with the school, like a problem or ... but she was always there. . I*

feel that I've been put in the position now that I can't because she's no longer his physio." (Ph2.ICD.Int2.)

Informal discussions with this particular physiotherapist during the observation period revealed that she felt unable to continue the relationship with this mother due to the excessive demands made upon her time and emotional energy, within the context of a demanding and full caseload. The physiotherapist had therefore negotiated a system of 'sharing' challenging families and children so that the team could offer a service in which one team member was not over burdened.

The process of mutual exchange was also evidenced in relationships between the chronically ill person and their family carer. It seemed that by using the strategy of mutual exchange, care-recipients were able to negotiate their uncertain illness trajectory while at the same time maintaining identity and a sense of purpose.

'It's strange to say because he was doing everything for me, but the relationship we have, it was like, he still needed me and doing everything ... well it was hard work for him but it was still me who said 'why don't we have this for tea' or 'have you done the packed lunches yet?'. So, yes, I was dependent on him, but he depended on me as well.' (Catherine, interview 3, phase 1)

'My family moved here for me so I can get a good education and I am going to be a doctor and earn a lot of money so that I can send them back to Bangladesh as rich people.' (Hanif, interview 1, phase 2)

Parents often described the process of adapting to the illness trajectory in relation to allowing their child a level of independence and privacy. This was a reciprocal arrangement that conferred a level of freedom and control on both parents and the child.

"I think I have let go a little bit now of Billy. I mean at one time it was ... I mean I couldn't go to the toilet because he would scream and ... so I think we've both grown

up a little bit. He knows he can't be with me all the time and I know that ... he wants to do his own thing as well." (Billy's mother, interview 1, phase 1)

One woman described at interview how she maintained her husband's social contacts in order to address his isolation while in hospital. Observation data highlight the skills and effort put into this apparently easy task, particularly in view of the fact that the patient could not speak and was severely emotionally labile for months after his stroke (exhibited extreme swings of mood from sobbing to hysterical laughter).

"... he was seeing his friend who he hadn't seen for a long time. He came to visit, he works away and I rang him so he came straight to see him. Oh he was sobbing a bit, yes. I haven't seen him sob for a long time and .... but then they both were laughing and joking and it did him good it did." (Matthew's wife, interview 1, phase 1)

Observation of this and other interactions between the patient, carer and friends, revealed exactly how much effort the patient's wife put into involving friends and making the visit a pleasant, happy time for them, particularly in light of Matthew's challenging and distressing behaviour. Reflecting on this observation data helped Matthew's wife to examine the skills and emotional strength required for this task and also to explicitly identify the reasons for applying this effort, which involved investing in the family's social and emotional future, for the mutual benefit of all concerned.

"He has other friends come up on a Friday, about 6 of them so they have the whole ward taken over. At least they put a smile on his face. Just how am I going to cope with it all when he gets home ... if he's in this state, you know? You know, I mean ... you just couldn't expect anyone to sit with someone like ... if he's going to be the way he is now, you know. I mean he may not be, you know. You don't know. It's just ... you see, if he's going to be like this we could never ask anyone to come and sit with him but if his friends are involved from the start .... one has even been helping me flush his peg ... fancies himself as a nurse I think (laughter)." (Matthew's wife, interview 2, phase 1)

The proactive process of ensuring that all parties gained something during the care-giving/care-receipt exchange was also demonstrated by the children, as the following observation record shows.

Observation period 4 with Kate, phase 2
Today, I watched while the children from class 4 went out to play in the small playground which is separate from the larger playground used by the older children. Playtime lasted for 30 minutes. It was a very warm day and the able bodied children all ran excitedly and noisily into the yard. Emma and Jade stopped running when they got halfway into the yard. Without speaking, they turned around and ran back inside the classroom. Each girl grabbed an arm of Kate's wheelchair and again running, they pushed her into the yard. Kate laughed and shouted 'Careful, I'll get another bone broke. Me mam will kill yous if I have to go back to hospital'. *The girls then slowed down and carefully and gently wheeled Kate over to the bench where myself and Mrs C (class teacher) were sitting. E & J then sat down on the ground next to the wheelchair. Without any discussion, all 3 girls began to sing a pop song and did some complicated arm movements in time to the song. They invited Mrs C & myself to join in. At the same time, 4 other girls had started a game with a skipping rope and one of these girls shouted for E & J to join them. E & J looked anxiously at Kate. Kate smiled and said 'Eye, go on, I'll teach Miss the dance.' E replied 'We'll not be long'. Kate then proceeded to teach us the arm movements and the words of the song. After around 10 minutes, E & J ran back to Kate, breathlessly sat down and again without a word, began the pop song. Following this, we all sat in silence in the sunshine until Mrs C rang the bell to call the children back to class. This time J pushed Kate's wheelchair and gently manoeuvred it over the step into the classroom while E held Kate's hand.*

This subtle exchange of practical care, social interaction and friendship was evidenced many times by the children, not least by Hanif who was an expert at hitching a ride in his self-propelled wheelchair by grabbing onto the arms of a passing electric wheelchair. The owner of the electric chair was usually rewarded with help with maths homework. This process of mutual exchange between the ill person and their chosen formal or informal carer appeared to mediate against the effects of the unpredictability and lack of control over aspects of the illness trajectory discussed earlier, by allowing people to conceptualise themselves as active

contributors to meaningful relationships. The ability to adapt to uncertainty was further demonstrated by strategies employed to normalise relationships within the biography of the chronically ill person.

4. Normalisation within the biography

Participants managed unpredictable needs and environments within the here and now by not planning too far in advance and not making any firm promises about those plans. Although fears and anxieties about both the past and the future were acknowledged, the over-riding concern for participants in both phases was to maintain a sense of *"normality"* within family life. This is linked with the strategy for making comparisons in which progress was usually seen in a positive light, despite evidence to the contrary, and is evidenced in the following exchange;

"She never complains. She's doing really well. We're coping very, very well." (Monica's mother, interview 1, phase 2)

This mother was interviewed again 6 months later and reflected on the previous 6 months in which her daughter had a major operation and was coping with a new diagnosis of diabetes.

"Nightmare, I don't know how we got through it. She was so exhausted and getting her to eat was a nightmare. She maintaining her weight now though, you know, a lot so I'm delighted about it." (Monica's mother, interview 2, phase 2)

This mother appeared to cope with the trajectory by appearing *"absolutely fine"* in the present, which allowed her to express past problems, and future difficulties.

"I think it's great she's doing things now, where she wasn't doing that before. Oh, God, I mean it might come to that ... where I might have to do more for her in the future but I don't at the moment." (Monica's mother, interview 2, phase 2)

In both phases, acceptance of chronicity seemed in part to be linked to a protection mechanism that emerged in that participants were able to share painful and deep feelings concerning loss and grief in their past and future biographies, but only within the context of being seen to be coping well in the present moment. This may be a methodological issue linked to a reluctance to share worries and anxieties with a comparative stranger. However, it is also possible to suggest that it is in part a consequence of the struggle for diagnosis, described earlier. The peri-diagnostic period was characterised by conflict and mutual mistrust between families and formal carers. It is possible to suggest that as a consequence of this struggle and confrontation participants felt it was necessary to be seen to be coping well in the present in order to confirm their rationality and re-establish equilibrium in the face of expert opposition and to deflect accusations of neglect or being over-anxious parents. This is also linked with the visibility of parenting a sick child – the highly visible nature of physical impairment coupled with the shear numbers of formal carers involved in the lives of chronically ill people makes them vulnerable to scrutiny and turns private life into public property.

This was evidenced by a subtle process of carrying out activities and decisions designed to normalise family life, in the sense that the illness and needs did not define daily life for patients and their families.

"She just goes to a family for respite which means I can have a break and do normal things with my little boy that don't revolve around a wheelchair. It's actually a retired couple and it's every month now and .. a week in the Summer and if we do need it any other time, it's available." (Rebecca's mother, interview 2, phase 2)

"I mean I've passed my test in January and ... it's lovely for Mon to get out and have fresh air, you know. When she was not feeling okay and she would sit in the house and never getting out. Now all she's got to do is sit in car, in the front, get a bit of fresh air and at tea time we go back in the house ... the kids think it's great."
(Monica's mother, interview 2, phase 2)

For the children, there were occasional references to their physical differences and impairments in relation to able-bodied people and in relation to their past selves. However, the over-riding theme was of similar normalising tactics in which their impairment and illness did not define their social and emotional lives. Sarah expressed this in terms of her obsession with a pop group; Liam talked abut his piano music; Monica about a wedding in which she would be bridesmaid. For example;

" We've already been on holiday this year. Before I went into hospital. I just took all the stuff ... for the feeds and stuff ... just give me I.V.s and stuff. There was a girl there. I got really friendly with her." (Monica, interview 1, phase 2)

In this study, normalisation is presented as a process of 'getting on with things' in the face of uncertainty that was characterised by an ability to set anxiety, fear and uncertainty to one side in order to re-establish one's roles and relationships following diagnosis.

Summary

In this study, three interdependent psycho-social strategies are presented as proactive processes undertaken by participants in order to adapt to unpredictability and uncertainty inherent in the illness trajectory. Comparisons within and beyond the biography of the chronically ill person is presented as the initial strategy embarked upon out of a desire for predictions to be made about short to long term goals and needs in order to place oneself on a continuum, an internal 'map' of severity of needs and progress. This course of action is presented as a psychological protection mechanism in which almost without exception, comparisons were favourable and placed progress and needs in a positive light.

Comparisons were also made within the time continuum of the illness biography. Past and present progress was analysed and reflected upon in order to make predictions about future progress. Important within this was the consistent presence of a specific, identified formal carer who was used to access information, practical support and mediation skills. This reduced conflict of needs within and beyond the person and the family and conferred a level of control over acute episodes of ill health. These and other normalising strategies combined to mediate the effects of unpredictable environments and needs over the uncertainty experienced within the illness trajectory. It seems that seeking out a helpful member of staff and then maintaining a relationship with them was a proactive process that participants engaged in order to reduce some of the uncertainty inherent in their illness experience and conferred some level of control over acute episodes and unpredictable needs. These findings have several implications for the organisation

and implementation of formal care for people with enduring illness and their families. This is the subject of the following, final, chapter of this thesis.

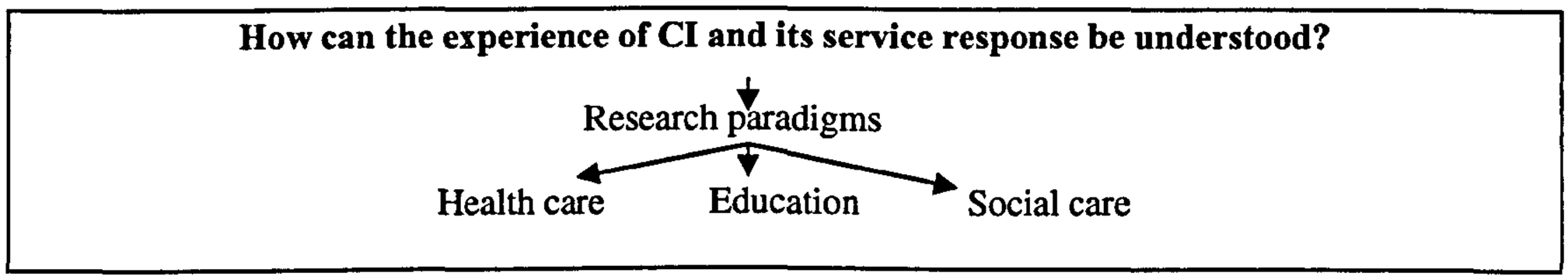
Chapter 9

Implications and reflections: An emerging theory of uncertainty management

Introduction

Aspects of the findings are discussed in the following sections in relation to the ways in which they inform pivotal questions that were posed in the literature review about the dimensions of chronic illness, and its exploration. Analysis is made of the ways in which this thesis contributes to knowledge about the experience of living with chronic illness. Attention is paid to the specific contributions made to method and methodology in this area, particularly with regard to sampling and the use of photography. Limitations of the study are discussed alongside suggestions for future avenues of enquiry and service development in the substantive area of chronic illness.

This chapter locates findings in current developments in the understanding of uncertainty in chronic illness and suggests that current knowledge of uncertainty is under-developed, particularly in relation to the experience of chronically ill children. The literature conceptualises uncertainty as an entirely negative experience, reactions to which are framed in the language of psycho-pathology. Knowledge about the human ability to make substantial, positive adjustments to the uncertainty inherent in chronic illness is a significant contribution to research in this area. It demands a re-conceptualisation of illness and disability as a tragic, negative event towards a process in which social relationships are preserved, effectively restructured and even improved. Attention is paid to the ways in which findings inform debate about current policies, such as the Expert Patient, for people with enduring needs. In particular, the ways in which continuity of carer can mediate the effects of chronicity across the illness trajectory is analysed.



This section explores both the effectiveness and limitations of the ways in which the study design contributes to understanding the experience of chronic illness and its service response.

Reflexivity

The influence of the researcher as an experienced nurse and family carer on the research process has been an implicit element of all aspects of this thesis. This section makes explicit two aspects of this influence in relation to firstly the process of managing and analysing data from two different contexts, and secondly in relation to wider debates concerning the tensions and contradictions involved in acknowledging researcher influence while ensuring transferability and trustworthiness.

Truth seeking or truth making?

The literature review shows that qualitative methodologies are already well-established tools for exploring the lived experience of chronic illness from the viewpoint of adults, children, family carers, and professional staff. Fewer studies exist that cut across both age and diagnostic categories as in this study. This study

used participants from a variety of ages, gender, social background, diagnostic and prognostic categories, taken from two very different contexts. This fact brings into sharp focus the debate concerning firstly, whether the analysis has been deductively, rather than inductively, driven in order to fit a preconceived theoretical framework, and secondly, applicability or transferability of findings to other demographic or diagnostic groups. These questions are often neglected in qualitative work and yet they are at the heart of concerns held by practitioners about the applicability of diverse studies to their own area of practice. Lincoln and Guba (1985) assert that researchers should show;

> *"the range of contexts to which there might be some transferability of findings and that adequate thick description of the context is needed so that anyone else interested in the transferability has a base of information appropriate to the judgement."* (pp. 124-125).

An element of this 'thick description' needs to include an elucidation of the way in which analysis is arrived at; this is particularly important in this study that assimilates data from two different settings. Having made the decision early on in this study to give primacy to the diverse voices of patients and children in this study, it was important to ensure that the analysis was not forced into a preconceived framework due to a desire to make these diverse voices 'fit' in some way. Glaser (1992) suggests that forcing, *"by preconception constantly derails it (*theory*) from its relevance"* (p.123). However, far from 'forcing' my data into one unified story, I experienced a very powerful scepticism about the fact that the theme of uncertainty management could emerge so strongly in each setting. In addition, I struggled against the emerging theory because, as a newly qualified staff nurse, I could not believe

uncertainty management was not common knowledge. I thought that I should have known this – the fact that it emerged so strongly from data surely suggested that professionals and academics alike must be aware of this phenomemon. This uncovering of 'ordinariness' seemed to contrast strongly with the quest for 'originality' that defines a PhD and created a central tension in the apparently mutually exclusive desire to contribute something new and note-worthy while at the same time reflecting the ordinary, everyday experiences of participants. Through a process of professional, academic and intellectual development, I began to believe that the findings represent a new articulation of professional reality – they are a reflection of the ordinary, everyday challenges of living and working with chronic illness done in a way that has the potential to change the way the reader views practice. Estabrooks' (1999) exploration of research utilisation was useful in this regard – he states that qualitative research can have 'conceptual utilization' in that findings can have the power to change the way an every-day phenomenon can be understood. Giacomini and Cook (2000) express this very neatly by referring to findings becoming either a mirror or a window to practice; for readers with no prior knowledge of the phenomenon, findings can provide a window through which to see aspects of life that would otherwise have remained unknown; for readers familiar to the area under study, findings can provide a mirror that allows them 'to look back on and reframe their experience' (Sandelowski, 2004. p. 1372). Using this analysis, I began to believe that my findings had the potential to both reflect and reveal otherwise taken for granted practices and experiences.

This growing belief in a unified theory created a new set of challenges. As my commitment to this new articulation grew, how could I be sure that my desire for completeness and combining data from two very different contexts did not over manipulate data analysis? From the start it was never my intention to create one complete jigsaw from two different data sets. I always felt the differences between findings would far out way commonalities; it was anticipated that analysis of differences would illuminate a fresh understanding of the meeting of chronic needs in different institutional settings by creating two different jigsaw puzzles and comparing the ways in which the pieces fit. However, as data emerged and I was able to return to the field and ask participants to check transcripts, the story of uncertainty management emerged so strongly in each setting that it was impossible not to assimilate a shared representation of uncertainty. The methodology used in the study allowed me to manage this process using theoretical sampling and constant comparison that allowed an iterative return to the field to explore emerging themes. The fact that participants were able to read and reflect on their interview transcripts allowed for a full exploration of themes in each setting. For example, the theme of making comparisons with others was identified early on in observation with patients. This was explored in interviews with patients and family carers in order to examine its properties. Theoretical sampling allowed for a return to the field to explore whether this phenomenon occurred in different environments (in this case, a Nightingale ward as opposed to a 6 bay ward). Without prompting for me, the theme emerged as strongly in the second phase, with children and staff giving many examples of the ways in which comparisons were important to them. This again gave

me the opportunity to explore this theme in interviews, and to return to the field if necessary. The fact of data collection in the first phase certainly made me more 'theoretically sensitive' (Strauss & Corbin, 1990) to the issue of comparisons in phase two; the number of times it emerged and the fact that people spoke spontaneously about this issue without direction or influence from me strengthens the trustworthiness of the emerging theory. Many examples of the data have been given in order that Kochs (1994) decision trail can be followed in terms of the decisions taken at each stage of the study. This allows the reader to judge whether the concept and linkage between concepts are *"sensible, logical, and verifiable"* (Morse & Singleton, 2001, p. 842).

This study would certainly have been less challenging in theoretical, intellectual and organisational terms had it been carried out in one site, with one diagnostic group, looking at one issue. The early shift in focus from multidisciplinarity to a broader inductive, naturalistic concern about multiplicity of voice in each research setting demonstrates the commitment to allowing findings to emerge rather than being committed to a pre-conceived study design. It is possible to suggest that the multi-site, multi-diagnosis study design strengthens the trustworthiness of findings, and points to their transferability and generalisability to other settings with other diagnostic groups. Consideration of whether findings from this study are generalisable or transferable must take into account the varied demographic, trajectory, and diagnostic groups included in this study, demonstrated in the *"thick description"* provided in chapters 7 and 8 of this thesis. Psycho-social

processes emerged that appeared to cut across diagnostic categories and were independent of contextual factors such as family dynamics or professional response to need. The concept of credibility referred to on page 76 of this thesis informs this debate by suggesting that a study has credibility and potential transferability when readers confronted with the experience can recognise it from their own experiences (Koch, 1994, Guba & Lincoln, 1989). I share Morse and Singletons (2001) opinion that demographic or diagnostic 'fit' is unimportant if the process or concept is pertinent to the new setting. It is my belief that the theory of uncertainty offered by this thesis has resonance and pertinence in other settings regardless of diagnostic or prognostic outcomes. Although context was important to participants in relation for example to the organisational and environmental influences on needs and responses to need, the emerging theory was also acontextual in that it had applicability over time, and was transferable to others institutions and settings in which chronic needs were addressed. As a practitioner, I believe that this acontextuality is vitally important if qualitative research is to earn its way in practice development. Just because a qualitative study is not easily replicable as in quantitative terms, does not mean that findings from one study (or context) can not illuminate practice in other settings. Morse and Singleton (2001) illustrate this by quoting a study that revealed the link between respect for privacy and the quality of relationships between staff and elderly male patients in a nursing home. I concur with Morse and Singleton's view that these findings can have resonance for the way I care for women with breast cancer in the community; the fact that data were derived from a different client group in a different setting does not negate this. This brings the debate back to a concern

highlighted early on in this study into the commonly held view that research should be diagnostically specific. It is only by carrying out qualitative studies such as this that we realise that diagnostic specificity can become contrived and does not necessarily reflect the reality of multiple pathology and multiple needs that forms the daily experiences of patients and practitioners alike.

This section has examined and analysed the central contradictions that occur when carrying out qualitative work that acknowledges a multitude of voices and contexts, while having a commitment to theory generation that can be applied regardless of context. The task of assimilating those voices in a way that truthfully and accurately reflects a representation of reality has not been easy. An eminent academic recently told me I was 'brave' to carry out a PhD based solely on qualitative work; when we discussed what she meant, she talked about qualitative work not having the 'security blanket' of reliability and validity factors when defending my thesis. Having reflected on this exchange, I believe that qualitative work is 'brave' on several levels. Rager (2005) recently brought attention to the 'compassion stress' that results from exposure to stories of tragedy and terrible illness. For me as a practitioner, the stress and subsequent 'bravery' comes not simply from hearing these stories, but in representing them in a way that remains true to the meanings ascribed by their owners while at the same time ensuring that any resulting theory has rigour and transferability. It is my strong feeling that the rhetoric of theoretical sensitivity and bracketing of prior experience gives us an excuse not to engage with the realities of living with or caring for someone with chronic, unpleasant, bodily needs. The challenge for qualitative research is to ensure that

findings have 'grab' (Strauss & Corbin, 1994) by remaining true to the experiences of participants in a way that does not pander to quantitative measures of reliability and validity, but that gives an honest, rigorous account of the decision trail in a way that allows the reader to view practice in a new way.

Methodology

The use of a symbolic interactionist approach to the interpretation of data was a valuable and effective tool in this study. The three main premises of symbolic interactionism (discussed more fully in chapter 3) resonated with findings on several levels. Firstly, actions can only be understood in relation to the meaning that people ascribe to their surroundings and the people in them. This is evidenced in this study by the interpretation of 'special events' and the ways in which participants used these interpretations to place their experiences on their own personal illness trajectory. At the heart of the emerging theory of uncertainty lies the fact that professional staff sometimes interpreted actions differently. Their meanings were based on short-lived acute episodes that were firmly orientated to the present and short-term future, rather than the entire biography of the chronically ill person.

Secondly, meanings develop from the social interactions between people; these interactions are symbolic because communication creates or produces language and other symbols. This is evidenced through the process of maintaining continuity of carer. Participants were able to understand, accept and adapt to uncertainty by

using social relationships with staff to define a shared, predictable biography on an unpredictable trajectory.

Finally, meanings are created and adjusted through the interpretive process: This is found in the strategy of managing the flow of information and making comparisons, in which participants interpreted and controlled the flow of information in relation to the changing meanings this information held about their prognosis, the causes of symptoms, and the severity of their illness in relation to others.

In a way, the tenets of symbolic interactionism resonated as much with my own journey of understanding as with the journey embarked upon by participants in this study. Goodman (1978) suggested that the notion of theoretical certainty is "*a pretentious muddle of the psychological and the pseudological – is unsalvageable*". (p. 159). Goodman's notion was of the creation rather than the discovery of truth and the 'adoption' of habits, strategies, vocabularies, styles as well as statements. I started my journey into symbolic interactionism as the struggle for an indisputable discovery of a theory (albeit one 'grounded' in the data,), and slowly my understanding resonated more closely with the tenets of SI in that truth and theory was simply an expression of meanings, interpretations, and actions based on those interpretations. This seems to have deep resonance with the emerging theory itself; that of participants who embarked on a struggle for indisputable facts and predictions about their illness, and slowly adopted habits and strategies that allowed for an acceptance of a reality created from an ever changing context that was no longer concerned with diagnostic and prognostic parameters.

The main limitation of using symbolic interactionism in this way was that it failed to explicitly address contextual and structural issues in this study. For example, the study did not focus in depth on the organisational context of care. One area for future development would be the effect of the tensions between acute, curable interventions and chronic, incurable needs on the work of professional staff. This thesis represents a journey of understanding, not only about the area under study but also about the ways of knowing about the area under study. Armed with this new understanding, I would embark on further studies using a more critical tool such as constructionism, that would allow a greater critical analysis of context than that allowed by the approach used in this study (Schwandt, 1994). Concerns about the context of care in this study and the difficulties in engaging in critical analysis of the context are at the heart of a personal concern that I have about the negative ways in which the work of professional staff and the experiences of people with CI are framed in the substantive bodies of research, and the type of research that perpetuates, rather than challenges the context, in which it takes place. I believe that it is only when research takes the next step into offering meaningful, practical solutions to the problems and paradoxes of such policies as 'Saving lives' and 'The Expert Patient' does it truly earn its way. The second half of this chapter offers reflections on these practical solutions.

Sampling

The literature review (Chapter 2) identified the difficulties in defining, measuring and responding to chronic illness. These difficulties were located in a debate about

the challenges of researching and understanding the commonalities and differences in experiences of CI. The methodological and sampling implications for future research are brought into focus by the findings from this thesis, particularly in relation to the experience of multiple needs and multiple pathologies. This study contributes to a growing body of work that explores generic, rather than diagnostically specific, aspects of living with chronic illnesses. Within this thesis, data were taken from specific client groups with definable chronic illnesses, namely stroke and various childhood illnesses including cystic fibrosis and muscular dystrophy. The majority of participants were found to have more than one diagnosed chronic illness that required intervention from formal carers. The resultant multiple, complex needs influenced the experience and management of uncertainty in several ways, concerning the management of information flow and gaining mastery over symptoms.

This brings into question the sampling process used in qualitative work, particularly in view of the fact that in the hospital setting, staff refused to give me access to participants until a diagnostic category had been reached. Pre-diagnosis was found to be a defining period within the illness trajectory in terms of dealing with uncertainty. Had I been less specific about my sampling group, access might have been granted much sooner in the process. The period of time before hospital admission was very significant to clients and their families in terms of beginning to understand and accept uncertainty. This was interesting since theoretical discussions concerning the lives of disabled people generally begin at the point of diagnosis and prognosis of the disease or illness that causes the disability (Anderson & Bury, 1988,

Swain et al, 1993). Since this usually correlates with a client's admission to hospital, this is necessarily where theoretical discussions and research studies begin to focus their attention. Similarly, in clinical areas that deal with disabled people, discharge plans have an underlying assumption that the person has never coped alone with a particular set of needs and will require particular services to help the family and the client cope with the often sudden and violent transition from being able-bodied to being disabled (DHSS, 1980).

This data begins to bring these assumptions into question, which shows how people coped with these new symptoms and fluctuated between denormalisation and normalisation during the pre-diagnostic period. Clearly, retrospective accounts of this period are valid and reveal new information about coping strategies. However, further research needs to be carried out in order to understand the ways in which formal carers could support people during the pre-diagnostic phase and could help them to establish effective strategies for dealing with uncertainty over the trajectory. For example, the time period between diagnostic tests for some cancers, entails a waiting period of several weeks for results, and this period is characterised by stress, anxiety and a need for information. Patients then receive a devastating diagnosis when they are already at an emotional and psychological low point due to the waiting period. Supporting patients through this period may have positive implications for the longer term coping strategies used by families.

Carers

As a result of the self-selection sampling tools used in some studies, research with carers tends to be conducted in situations where carers consented to and adopted the role of carer. Because this study followed through the patient from diagnosis and encouraged retrospective exploration of the time before diagnosis, a picture was built up of the processes involved in adopting the role of carer, from gendered assumptions that daughters and wives would become the main caregiver through to the fact that some reported a feeling of gladness that they could repay care giving activities given to them during their previous relationship with the patient. The fact that the study required a carer to be identified fairly early on meant that the study may have contributed to the process of adopting a role otherwise not wanted. For example, Anne's daughter reported unwillingness to become involved in her mother's discharge home and worried that being elected as spokeswoman for the study gave staff an impression of willingness to care for her mother after discharge. This study allowed for the study of the adoption of the carer role and the accompanying psycho-social process that ran alongside the patient's quest to embrace uncertainty.

Methods

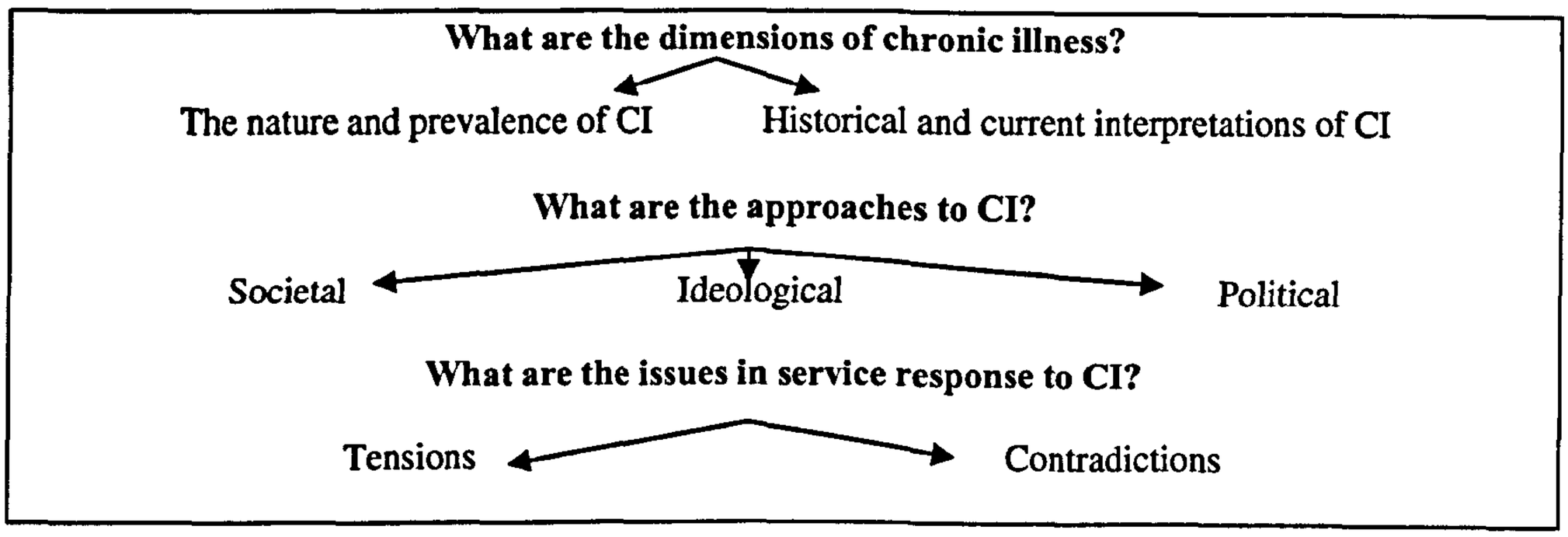
The use of photographs is uncommon but is slowly increasing in the field of biography work. More common is the use of drawing pictures as a way of allowing children to engage with the research process, or of using photographs taken by the researcher rather than the participants (Haggstrom et al, 1994). Allowing children to

take photographs in this study was found to be an effective and revealing way of encouraging the children to engage with the research process and to break down barriers between the researcher and the child. This created an atmosphere where it was clear to the child that I was interested in them and their lives and that the research process was non-threatening and relevant to their experiences. Asking participants to take their own photographs represented a subtle shift away from the ethnographic tradition of taking a 'snap-shot' of a culture and applying a research interpretation to it. Instead, the children were asked to choose their own photographic subjects and place their own interpretations on these. This shift towards allowing participants to be active and competent interpreters within the research process is consistent with the current desire within research and health care policies to access the opinions and wishes of patients. The use of photography could be extended in a number of areas, not least in the area of elderly care, patients who traditionally have little say in what happens to them. In addition, the use of photography could give us access to the voice of people who have traditionally been excluded from research because of speech or hearing impairments or those who have learning difficulties.

The use of questionnaires in this study were intended to be an efficient way of gaining access to the views of a variety of professional groups from a variety of organisations. Although they succeeded in this aim, the time taken in developing and piloting the questionnaires rendered this less efficient than anticipated. In addition, the fact that questionnaire data sometimes contrasted with observation data led to concerns about whether the wording and style of questions inhibited, rather than encouraged, true reflection about role and responsibilities. Observation gave access

to behaviours and actions, whereas the questionnaire gave access to interpretations and meanings behind those behaviours. Interviews with staff would have added an extra layer of access to the actual working process of interpreting, rather than the end product that was captured in the questionnaire data. In particular, the questionnaire data sometimes seemed stilted and contrived and people seemed to be telling me what they would do in ideal circumstances, rather than what they would do in practice and why. Time constraints did not allow me to interview some of the staff who completed the questionnaire data; this would be an area of further development of the emerging theory of uncertainty from the viewpoint of clinical staff.

Dimensions of chronic illness



The following section analyses the contribution made by this thesis to the theoretical and practical questions posed in the literature review.

Current knowledge

The literature review in chapter 2 identified the challenges in determining the exact nature of chronic illness due to its diversity of diagnostic and prognostic elements, and the diverse service responses to these elements. Difficulties in defining chronic illness were discussed in the literature review in relation to the varied trajectories that an illness might follow according to its diagnostic and prognostic parameters. These difficulties create challenges in measuring the prevalence and the most appropriate responses to chronic illness. This was evidenced in a discussion about the varied historical approaches to meeting chronic need that involved institutional responses to illness and inherent difficulties in responding, both politically and practically, to chronic need. These difficulties were located firmly within the fact that political and practical responses continue to be diagnostically specific in their approach and that

there continues to be societal, political and practical expectations of cure or rehabilitation. This leads to societal and ideological tensions in finding special places for special people within resource constraints, set against a society that continues to focus on ways of eliminating chronic need, and placing the locus of responsibility for health with the individual, rather than in meeting the complex, temporal needs of people with chronic illness.

What does this research add?

Findings suggest a common set of experiences and processes undergone by participants that cut across diagnostic and organisational groups. These processes are located firmly within the shared experience of uncertainty, that both fluctuated over the illness trajectory and also had a constant, unwavering element to it. It is possible to suggest from this that any definition of chronic illness should include an acknowledgement of uncertainty about cause, diagnosis, prognosis, needs, and responses to needs. Such a definition might encourage professional responses to chronicity that openly acknowledge and address the uncertainty inherent in any illness trajectory.

The central argument of this thesis is that uncertainty over the illness trajectory cannot be reduced or removed and that chronically ill people accept and manage the prognostic limits of knowledge within a process framework that is temporal and is located in the relationships between patients, carers and professional staff. The findings from this study point to the fact that theoretical exploration of uncertainty may have a number of implications for service provision for people with

CI and their families. The explicit recognition of uncertainty may assist practitioners to articulate their role, which so often involves giving support to people with multiple chronic needs over a life-span. In particular, the identification of uncertainty can assist all participants at the interface to accept the curative failure of medicine, and to offer a rationale for support over the illness trajectory. The need to support people through uncertainty provides an explicit rationale for providing continuity of care(r) across chronic episodes. Several points emerged that have implications for the organisation and implementation of services for people with enduring needs.

- The ways in which chronicity and uncertainty in the illness trajectory are taken into account in the management of enduring needs
- The ideological and practical tension between independence and support for chronically ill people
- The primacy of professional responses to chronic needs whose goal is continuity and support rather than recovery and rehabilitation.

- **Chronicity and uncertainty in the illness trajectory**

A shared experience of chronic illness to emerge from this study lies in the exploration of the nature of chronicity and its service responses. Participants embarked on their illness journey with little or no knowledge of the trajectory that was about to unfold. Formal carers found it difficult to share their own interpretations of the trajectory and the ensuing struggle for information led to a gradual realisation of the limits of prognostic predictions. The fact that formal carers

were more interested in current needs rather than past coping strategies or future fears created real tension in the relationship with patients and families. Participants in this study were often found to locate fears, anxieties and problems in the past or the future of their illness trajectory. This was found to be as a result of accepting chronicity as a temporal experience and being seen as doing 'a good job'. This has implications for formal carers – the fact that families need to be seen to be coping makes it difficult to request help in the here and now.

It is possible to suggest that the management of uncertainty represents an aspect of care provision that becomes an implicit, tacit aspect of the professional role, that once mastered, represents an element of the 'expert' in the transition from novice to expert (Benner, 1984). Indeed, informal discussion with colleagues about the findings of this thesis led to discussion about uncertainty management as the 'essence' of our work as primary care staff. Brashers (2001) suggests that this area of practice remains tacit and poorly understood as a result of the Western paradox between creating certainty through science and medicine and yet not being able to confront the most obvious certainties that we will all have lived experience of illness and we will all die. Overall, the literature suggests that it is human nature to attempt to reduce uncertainty rather than managing it, and this leads to information programmes designed to reduce uncertainty, with the unproven assumption that this is the best route to decision making (Brashers, 2001). However, the media brings us news of uncertainty every day, from international threats such as international terrorism, and infectious disease such as SARS and HIV, to more personal concerns such as fluctuations of interest rates or pension funds. And yet we all manage to

function and make decisions that affect us individually and as members of wider society. We can therefore assume that uncertainty and anxiety are not synonymous and that "reducing uncertainty" is not the same as "managing the effects of uncertainty" (Brashers, 2001, p. 489). Giarelli (1999) notes that although uncertainty cannot always be reduced, anxiety and the wish to reduce uncertainty can be pathological; it is logical to suggest therefore that initiatives that assist people with CI to manage, rather than reduce uncertainty will promote both physical and mental well-being among chronically ill people and their families.

Current understanding of uncertainty management

Interest in medical uncertainty has pervaded the medical and medical-sociological literature for many years since Talcott Parsons (1951) identified the source of medical uncertainty as the *"limits of control"* that medical staff encounter. A large body of work on medical uncertainty now exists, dominated by work by Renee Fox, an American sociologist who first identified the process of *"training for uncertainty"* (Fox, 1957, p.410) undergone by medical students. In her critique of medical uncertainty, based on 40 years of interest in this area, Fox (2000) identifies the conceptual shift in interest towards the increasing importance of medical prognosis, that has resulted from the international increase in chronic illnesses. She cites the fact that prognostication,

"is likely to be threatening both to the physician and the patient, because it reveals not only medical uncertainty and limitation, but also medical fallibility." (Fox, 2000, p. 415).

This thesis highlights the internal struggle experienced by participants who wished for information about the illness trajectory and who gradually became aware of the limits of the prognostic capabilities of professional staff. Christakis (1999) noted that medical staff believed that negative predictions about prognosis would lead to a 'self-fulfilling prophecy effect' (p. 415) in that patients would give up and die within the prescribed period. He identified that for this reason, medical staff avoid, play down, or become falsely optimistic about prognostic forecasting. He suggests several reasons why the management of prognostic information deserves attention. Firstly, the ongoing technological and medical advances make predictions a moving target that must be constantly re-evaluated in light of new developments. Secondly, the ideology of patients as consumers first introduced in the 1980s is expressed today in relation to the ethical imperative of gaining informed consent for every diagnostic and therapeutic intervention offered. Informed consent relies on explanations of expected outcomes, risks, and possible side-effects. Fox (2000) suggests that the kinds of forecasts about suffering, pain, and quality of life, that this implies, carries both staff and patients into "*the realm of questions of meaning and of spiritual beliefs and uncertainties.*" (p.416).

While offering a powerful critique of the pretence of certainty offered by Western medicine, this substantive body of work appears to have little to say about the patient's experience of uncertainty or of the experience of professional groups other than medicine. The main substantive area to analyse the experience of uncertainty from the adult's view point is in the area of psychology. For example, inability to plan for the future has been shown to lead to psychological distress by

Barbarin et al (1985). Recognition exists within the literature that uncertainty invades all stages of the illness trajectory (Hilton, 1992; Cohen, 1995; Ellis-Hill, 2000). However, few studies exist that explicitly demonstrate conceptual links between the experience of uncertainty, unpredictability and service response to this experience in chronic disease management. In particular, little is known of the uncertainty experienced by chronically ill children. In general, understanding of the ways in which uncertainty pervades the illness experience *"continues to be atheoretical"* (Mishel, 1997, p.74).

Understanding of uncertainty management in chronic illness focuses largely on work carried out by Mishel (1983) who devised an 8-point uncertainty scale during her quantitative work with parents of chronically ill children. She defined uncertainty as *"the inability to determine the meaning of an illness-related event"* (1988, p.226) and asserts a strong link between the experience of uncertainty and the ability to recognise and deal effectively with symptoms. Cognitive ability to cope with chronic illness could only be achieved, according to Mishel's early work, when uncertainty was resolved. Recently, a conceptual shift has occurred in Mishel's work, in which she now identifies the ways in which uncertainty can be maintained, as well as eradicated, during the illness trajectory. More recently, Cohen (1995) built on the work of Mishel and identified sustained parental uncertainty as a second chronic condition situated in and dependent upon the disease process. She suggested that professionals often fail to acknowledge and address the degree of uncertainty and fear of the future which lies beneath parents' conscious awareness.

This thesis argues that unpredictability and lack of control over needs and events over the time continuum, coupled with an unpredictable external environment, contributes to a very particular experience of uncertainty within chronic illness that influenced the ways in which relationships and interfaces were negotiated. Uncertainty was linked with coping but was a constant feature of life with chronic illness; ability to cope with uncertainty did not represent an elimination of uncertainty but rather an embracement of its long-term existence. This embracement allowed for the successful resolution of conflict at the interface and allowed positive, therapeutic relationships to be maintained across the illness trajectory.

Development of a theory of uncertainty management

In his discussion of qualitative data analysis, Strauss (1987) differentiates between formal and substantive, or empirical, theory. This study drew from the experiences of participants in both hospitals and schools, and as such was undertaken across the substantive fields of health, social care and education for children and adults with chronic illnesses. The literature review demonstrates the common professional, theoretical and empirical ground between these areas. This study contributes to the development of a formal theory of uncertainty management in chronic illness and disability. The substantive theory of uncertainty has been outlined in the previous chapters. These findings can be further developed into a formal theory of uncertainty management that is located firmly at the interface between patients, families and professional staff, rather than processes that individuals embark upon. Moreover, this theory can only be understood and examined in the context in which data emerged.

For example, findings show how organisational, social, and physical environments caused and maintained the experience of uncertainty for participants.

In this study, the process of adapting to uncertainty is presented as the way in which the chronically ill person and family define their relationship with the illness, with each other, and with professional staff. The emerging theory identifies causes and consequences of uncertainty and demonstrates the processes by which mastery over fluctuating uncertainty over the course of the illness trajectory was gained (the process of understanding), the process of managing constant, background uncertainty (the process of accepting), and how professional staff work with chronically ill people and their families within an uncertain context (the process of adapting). In this study, uncertainty in chronic illness is defined as: the inability to understand, predict, or control, the causes, consequences, or responses to changing physical and psycho-social needs over the course of an illness trajectory. Adaptation to uncertainty is defined as: The ability to understand, accept and adapt to the causes, consequences and responses to changing needs over the course of an illness trajectory, using strategies that confer understanding, prediction or control over the uncertainty experience.

Three psycho-social strategies are identified that are interdependent, complex and time focused and support the process of adapting to uncertainty. These strategies are making comparisons with the self and others, managing the flow of information, and maintaining continuity of carer. These strategies often supported acceptance of uncertainty, while at the same time creating greater uncertainty. Making comparisons enables the ill person and their carer to locate the self on an ever changing illness

trajectory that is located in the past, present and future of the ill person. This supports the process of understanding the illness journey. Managing the flow of information allows the ill person and carer to control the elimination or maintenance of uncertainty and contributes to the process of accepting uncertainty as an inherent element of the illness journey. Maintaining continuity of carer enables the ill person and family to manage their relationship with professional staff throughout the illness journey and to predict service response to their needs. This supports the process of adapting to uncertainty across the illness trajectory.

Presentation of the process of adapting to uncertainty suggests an uncomplicated, easy transition from being able-bodied to chronically ill, despite the devastating physical and mental threats it poses. For some participants, adaptation to uncertainty was a constant quest that remained constantly out of reach. Failure to understand, accept, and adapt to uncertainty led to conflict and distress that is located within the interface triad. The factors that influenced adaptation to uncertainty were:

1) Co-operation vs. animosity within the relationship triad

2) The ability vs. the failure to make sense of a new 'normality' in family life

3) Acute, curative vs. chronic, restorative model adopted by professional staff

The conflict that resulted from lack of co-operation between mutually antagonistic members of the interface triad, led to difficulties in dividing and negotiating care at each stage of the illness trajectory and therefore increased

uncertainty and inhibited management strategies. Cohen (1993) describes this as 'situational uncertainty'.

The ability to adapt to a new way of life within the context of the chronic illness influenced adaptation to uncertainty. Selder (1989) analysed the ways in which adults coped with major life transitions and demonstrated that a reduction in uncertainty resulted from recognising the permanence of change. In this thesis, failure to accept a new normality represented a strong wish to return to certainty about the body and about previously taken for granted health. This correlated strongly with a failure to understand and accept uncertainty as part of the illness journey.

Finally, the ability of a member of staff to see beyond the diagnosis and get to know the patient's biography and chronic needs was a key determinant in whether a participant was able to adapt to uncertainty. Becker et al (1993) explored the experiences of adults who suffer asthma attacks and suggested that patients had little confidence in professional staff who they perceived were not as knowledgeable as they themselves about their illness management. In this study, failure to treat individual chronic needs within the context of the person and family contributed to the sense of 'unknownness' that participants felt, and contributed to inability to understand, accept and adapt to uncertainty.

- **The tension between independence and support**

The second main area of debate to arise from findings is a consideration of the ways in which service providers can balance the competing requirements to both support

and promote independence for people with enduring needs. Thorne et al (2000) suggest that the mismatch between the realities of chronic needs and political and practical responses create a number of contradictions, not least that, "*the two idealized qualities of compliance and self-reliance become mutually exclusive.*" (Thorne et al, 2000, p. 304). Research indicates that people with CI increasingly use alternative therapies and self-management techniques that would be labelled as noncompliant by professional staff (Thorne et al, 2000). This is evidenced in this study by the tensions identified in the special school between provision of therapies and aids to assist walking, and the choices made by pupils not to walk, that were guided by their own prioritisation of social and emotional needs. The findings from this thesis point to a situation that cuts across diverse diagnoses of CI such as stroke and Spina Bifida, in which the chronically ill patient could only be compliant with the assistance of a member of staff willing to offer support, respect, and trust, and that self-reliance depended on maintaining supportive relationships over the time continuum. It is possible to suggest that participants in this study could only become self-reliant with the help of a member of staff with whom they shared a biographical history and who was able to assist the 'juggling act' identified in chapter 8 between bio-physical therapeutic demands and lifestyle choices.

'The Expert Patient' (DoH, 2000) exemplifies the current political emphasis on self management of chronic illness, re-inforced via National Service Frameworks for the care and support of people with complex needs over a life-time. The findings from this thesis, particularly the emphasis on continuity of carer, at first glance are entirely contrary to the emphasis on self care. However, the emerging theory in this

thesis suggests a model of expertise that is reliant on knowledge of the health, social care and educational systems in which people with chronic illness live and work, and an expertise in psycho-social processes that capitalise on otherwise taken for granted processes such as making comparisons and managing information flow. This then leads to the conclusion that self- efficacy and temporal support are not in fact mutually exclusive but that, for people with chronic illness and their families, they are intrinsically linked; participants could not reach a level of 'expertise' that led to self-management without reliance on trusted members of staff. Similarly, staff only felt able to allow people to make decisions regarding self-management within a framework that was built on intimate biographical knowledge of the patient and family. This calls for an entirely different approach to the current interpretation of expertise in which patients are left to 'get on with it' (Sam's father, interview 1, phase 2) in a way that creates and maintains uncertainty, to one in which, with supportive partnerships between patients and staff, uncertainty can be managed and minimised. These findings therefore have particular relevance to the very recent introduction of case managers for people with complex, chronic needs, who have the express aim of reducing repeated emergency hospital admissions for this client group (Hutt et al, 2004). The exact ways in which these case managers will select and manage their caseloads remains to be seen – clearly, the findings from this thesis call for strong emphasis to be given to psycho-social support and continuity to be built in to the emerging role in order to balance the apparently competing demands of self-care and support.

This will be no easy task since data from this study indicates the difficulty participants sometimes had in having confidence in their caring or self-caring skills, expressed, for example, in a refusal to look after another child with chronic needs. This flags up a central contradiction in the concept of the 'expert patient', that we expect patients and their families to value and have confidence in their (self) caring skills in a society that neither values, nor has any legal, ethical, or structural confidence in the ways in which we meet the needs of chronically ill people. Wilson (2001) identifies several paradoxes and contradictions in the application of the Expert Patient, not least the competing expectations of self-care and compliance with technical and medical management of the disease process. It is interesting to note that there is no exact definition of what constitutes an 'Expert Patient' in policy documents, although the emphasis on knowledge built up over time about self-management assumes a definition of expert that relies on experiential rather than education expertise (Wilson, 2000). In particular, expertise is largely focused on the bio-physical management of a chronic illness and relies on technical interpretations of chronic illness. The expectations of self-reliance, within a political context that is investing heavily in primary care for people with chronic needs, leaves unanswered questions about the ways in which continuity of carer can be developed and maintained. It is possible to locate the contribution made by this thesis to understanding the causes of uncertainty in analysis of these contradictions.

Firstly, the Western view of professional as expert provider of a cure is brought into question in light of findings that suggest that individuals often have a far more sophisticated knowledge of their long-term needs than professionals (Brown &

Piper, 1995). In relation to this study, it seems that lack of confidence in the ability of professional staff to co-ordinate and manage multiple needs created uncertainty and unpredictability that was overcome by having continuity of chosen carer. The struggle undergone by participants for a non-existent cure can only be viewed within the context of Western society that gives primacy to physical and mental well-being and increasingly emphasises personal responsibility for health. Uncertainty results from the lack of information given by staff who are afraid of dashing hopes and limiting recovery by giving an honest appraisal of the limits of their curative capabilities. It is possible to suggest that case managers must develop the confidence, based on intimate biographical knowledge of the patient and family, to give an accurate assessment of prognosis (or to be honest about the uncertain nature of the prognosis) and to address the support needs that ensue from that news.

Secondly, the new NSF for long-term conditions (DoH, 2005) is representative of an emerging recognition of the temporal aspects of chronic illness; it is no longer sufficient to meet chronic need within acute, reactive episodes of care. This resonates with findings from this thesis that point to the biographical, temporal needs of families. Although data collection and analysis in this study were largely located in institutional settings, some data were collected in participants homes; and information that participants chose to share was both prospective and retrospective; from this an imaginary biographical map was created that was different for each person, but was firmly located within the context of relationships that were largely independent of the institutions in which people lived and worked. The fact that participants had needs that were experienced in every context, both primary and

secondary settings, demands a natural extrapolation of findings from institutional settings to primary and intermediate settings, in which chronic needs may be met. This extrapolation is entirely consistent with the current political drive towards family based, community care for people with chronic needs.

Listening and responding to biographical stories of chronic illness requires imagination and an ability to extrapolate accounts of fears and anxieties located in the past and future into present needs. Primary carers are particularly well placed to carry out these tasks. Primary care staff in particular often share a biographical history with families and are able to locate past and future into present needs. Care plans are not just located in the present but extrapolate needs into the future thus offering patients and families a psychological safety net in which they can say "We're fine at the moment but it's nice to know you're here just in case." Community nursing work often involves giving out of hours support and assistance to clients and informal carers, as a result of what Bulmer (1987) calls 'affective ties' between clinical staff and people on their caseloads. This study highlights the importance of these ties and suggests that organisational strategies should be employed in order that relationships are not maintained on an ad-hoc basis.

Intermediate care also has the potential to bridge the gap between the concept of the Expert Patient, presented in Our Healthier Nation – Saving lives (DoH, 1999) with its emphasis on self-care and individual responsibility for disease management, and the competing expectation of compliance with complex disease management regimes (Wilson, 2001). The time period since data collection has seen growing developments in intermediate care for people with enduring needs with the aim of

bridging the divide between hospital and home. The imperative to assist patients and their families to come to terms with chronicity and accept the limits of cure and prognostic capabilities rests firmly, although not solely, with these types of institutional responses to need. The very fact that the language of 'intermediate' care is beginning to supersede 'rehabilitation' shifts the emphasis from cure and recovery to support and normalisation over a life span. Intermediate care units offer a new opportunity for people to be allowed to come to terms with uncertainty in an environment that allows for continuity of care and the opportunity to spend time with other patients in order to learn about the trajectory in a supported manner. This is discussed further in the following section.

- **Professional responses to chronic illness**

The final area for debate to arise from findings focuses on the ways in which service providers respond to chronic need across the uncertain illness trajectory. Continuity of chosen carer seems to cut across boundaries created by the 'clinical gaze' (Foucault, 1976) by allowing participants to create therapeutic environments using staff with whom they share a biographical history. This can be seen to transform a potentially repressive power inherent in the demands of compliance, into a positive power that allows chronically ill people and their families to become self-reliant. The emerging picture is of needs being framed within a confused and increasingly discretional health and social service (Twigg, 1997), and professionals who frame non-compliance as irresponsibility, and selfishness, contributing to the victim blaming culture still evident in our society (Hess, 1996, Thorne et al, 2000). And yet,

the contrasting evidence in this thesis is of professionals willing to go further and recognise the significance of chronic illness in and of itself, and to create therapeutic environments and opportunities that spanned chronicity rather than cut it into manageable acute chunks. Thorne et als' (2000) thorough analysis of attitudes to patient expertise in CI is overtly critical of professional construction of need that disempowers and is counterproductive. However, in their final analysis, they recognise that *"there are certainly exceptions (and patients in our study are quick to acknowledge the enlightened professionals they encounter)."* (p. 309). This study leads to a re-conceptualisation of patients with chronic illness as being expert at managing uncertainty using psycho-social processes to locate one-self on the illness trajectory and control unpredictable needs and environments with the help of supportive practitioners.

Freeman et al (2000) carried out a scoping review of continuity of care and divided concerns about continuity into three main aspects; continuity of staff, continuity of information, and continuity over time. The literature largely fails to identify the reasons for advocating continuity, although it is generally regarded as being a desirable aim in health and social care (Hodgkinson & Lester, 2002). It is possible to suggest that the emerging theory of uncertainty provides a rationale that professional staff can use to justify the provision of continuity in order to mediate the effects of an uncertain prognosis over a life span. Kralik et al (1997) conceptualised relationships between patients and nurses as being one of either engagement or detachment, each being wholly dependent on the behaviour of the nurses. This study takes this further by examining the role of the patient in this relationship; rather than

being passive recipients, this study conceptualises patients as active recipients of care who underwent a process designed to seek and maintain a relationship with a formal carer based on perceived reciprocity and mutual regard. This has implications for the ways in which co-ordination and responsibility of care is shared between members of multidisciplinary teams. Some disciplines, notably mental health and learning disabilities, allocate a key worker chosen from a variety of disciplines who has overall responsibility for co-ordination of care. This provides clients with continuity of care and more importantly continuity of carer. The ways in which key workers are chosen appears to be based in organisational factors rather than patient choice. Perhaps in future, patients could be offered the opportunity to choose their own carer in order to make the process of continuity a reciprocal, explicit arrangement.

Clearly, a redistribution of power between patients, families and service providers would be required in order to carry out this arrangement. Wilson (2000) suggests that at the heart of the Expert Patient lie questions about the distribution of power between chronically ill people and service providers. Foucault's (1976) notion of power suggests that the expectation of individual responsibility for health contributes to 'panopticism', literally meaning 'allseeing', in which society is kept under constant surveillance by 'experts' who set standards about fitness and other aspects of health promotion and prevention. Recent developments in primary care, for example the Sure Start for parents in underprivileged areas now means that even the most private areas of home life is subject to the gaze of clinicians, under the guise of holistic care. Foucault referred to this as 'pastoral power', where "*the most intimate areas of the patient's life, including their home, are now open to*

surveillance (Wilson, 2000, p. 139). It has been suggested by several authors that although the Expert Patient is to be applauded for highlighting the formal existence of chronic need for the first time in a way that seeks to empower patients and increase self-esteem; its inherent notion of pastoral power and public scrutiny can be seen to empower and suppress simultaneously. The findings from this thesis highlight the fact that participants felt the tension between public and private rights and responsibilities keenly, and managed this by maintaining continuity of carer.

At face value, provision of a chosen carer to provide continuity seems contrary to political expectations of self-reliance and resource cuts. In addition, it may seem naïve to suggest what at first seems like a huge commitment from staff. However, findings from this study suggest that this system is in operation in an ad hoc manner that is unsupported organisationally and structurally. To allow staff to formally identify those patients they feel able to offer continuity to would allow for holiday and sickness cover, and would allow for formal identification of complex cases that may require shared care(r)s to be allocated. The fact that participants actively sought experiential and technical knowledge from the pre-diagnostic phase onwards has implications for the ways in which formal carers communicate with families from the very start. The process of accepting uncertainty, via management of information, was found to be multi-layered and temporal and depended on more than simply having technical or medical information about an illness. The fact that people actively engaged in seeking information from a variety of sources has implications for the type, nature and timing of information given by staff. Professional staff sometimes assumed that a person was unable to receive

information that may be detrimental to hope or motivation in relation to their progress. However, people already held opinions about their progress that they had no opportunity to reflect on in terms of emotions or accuracy of opinions. This is a lost opportunity for all parties. In particular, it may be possible for formal carers to couch information within an account of events and procedures that the chronically ill person might encounter over the illness trajectory.

This thesis show the ways in which participants managed the lack of prognostic information using strategies of making comparisons and managing information flow. These findings suggest that in seeking participation, people with chronic illness do not necessarily want to be involved in technical decisions about their care, rather they are seeking expertise from professionals to help them understand their illness within the context of their biography. When it transpired that professionals were unable to give them certainty in relation to outcomes, participants were able to accept this. Under these circumstances participation can be re-defined as a two way sharing of knowledge with the professional imparting their expertise and the limitations of this, while the patient/carers provide contextual information on the impact the illness has on their lives and how they are going to integrate the future management of the condition into their daily lives. This often spills over into considerations of their social role and their family relationships. The findings from this study suggest that participants became adept at finding their own answers to these questions, particularly when they had continuity of carer. What emerged was that, far from becoming more ill and more distressed by negative prognostic information, participants were able to manage this information as long as they had

psycho-social support from professional staff, managed within a process of mutual exchange. This has important implications for the ways in which continuity of care is managed within hospitals and special schools. It is possible to suggest that the trajectory framework can be used by professional staff to understand and manage the course of the illness, but that this knowledge presents challenges in passing this on to chronically ill people themselves who struggle to make sense of their illness journey. The ways in which the flow of information was managed in this study highlights the need for enabling discussion of aspects of care often regarded as taboo and for strategies to confront, rather than avoid, the curative failure of medicine.

Reflections

This thesis began with an analysis of my frustrations and awareness about the contrasts between the individualised, dedicated care delivered at hospice level to cancer patients and the less highly developed care given to chronically ill patients at hospital level. It seems that the theory of living with uncertainty draws parallels with cancer care. In the past thirty years, research by Bond and Bond (1986) and others on diagnostic and prognostic information given to patients with cancer has led to an understanding of staff-patient relationships in situations where, like chronic illness, uncertainty is a day to day reality for staff and patients alike. Research has shown that nursing and medical staff are traditionally reluctant to communicate with terminally ill patients and to deal with uncertain issues for many reasons concerning resources, the ward environment and work organisation (Payne & Firth-Cozens,

1987). An awareness of these issues has led to major changes in services for terminally ill people. For example, in many areas of the country, the hospice movement is seen as an umbrella of care encompassing community, hospital, and hospice care. In those directorates where this ideal is a reality, the use of flexible staff means that patients can often be cared for by the same nurse, or group of nurses, at home and in the hospice (Field & James, 1994). In addition, day care facilities, where available, give patients an opportunity to meet with one another and discuss problems and feelings with each other. It has to be said that at present this system is often ad hoc and difficult to implement but it does go some way to addressing the issue of continuity of carer, and of providing contact with other patients in a way that builds on the coping strategies used by patients and their carers.

However, the fact is that much of the hospice movement is funded by charitable monies and Government grants. If the findings from this study were to be taken forward they would require vast amounts of resources to cater for the ever increasing numbers of chronically children and adults in this country. It is possible to suggest that if as a society we were less concerned about finding genetic, eugenic or bio-medical solutions to chronic illness, and acknowledged, instead of fighting the uncertainty of illness, it would be possible to divert resources to the meeting of real need over the illness trajectory that allows for the sorts of care seen in cancer services. This would provide the sorts of flexible policies and services set up by and for the "contingently able bodied" people that Marks (1999) refers to in the literature review on page 69.

Future avenues for enquiry

In the literature review, the challenge of defining and measuring CI are located in the diversity of experiences and trajectories experienced by chronically ill people. This study contributes to a body of work that explores the common processes that cut across diagnostic groups. Not least, this study demonstrates the difficulty in categorising participants who often suffered multiple diagnoses, which led to multiple conflicting bio-physical needs, and required complex management strategies. Since quantitative studies often exclude participants with more than one CI diagnosis, the extent of this problem merits further exploration in order to more fully understand the responses made by professional staff to the challenges of multiple needs.

Regardless of diagnosis or prognosis, findings from this study show that participants engaged in psycho-social processes within relationships in order to manage the uncertainty inherent in their trajectories. This study drew from experiences of people with varied trajectories, ranging from stable, fluctuating, to deteriorating needs. Further research is needed to explore whether the processes identified in this thesis can be applied to all children and adults with chronic illnesses. In particular, the experience of chronically ill children who attend main-stream school remains to be explored; it may be that children and their families are largely unable to create and maintain the internal trajectory map, described earlier, without being able to make comparisons with other chronically ill children. The challenges of main-stream education may require different strategies for dealing with the uncertainty of chronic illness.

The fact that participants in this study actively went about seeking out others in similar situations in order to make comparisons underlines the importance of support groups. The process of comparisons is touched upon by Cohen (1995) in her study of parental uncertainty in relation to avoidance of words and questions that heighten the uncertainty experience. This study suggests that the process of making comparisons runs deeper than simply sharing experiences and gaining experiential information. It is suggested that formal carers need to be aware of the fact that participants usually made favourable comparisons as a psychological defence mechanism. Further research is needed to understand situations in which the person with illness is clearly desperately ill compared to those around them. In addition, formal carers need to be aware that people make comparisons in order to locate themselves in the illness trajectory. This carries with it hopes and fears for the future that chronically ill people and their families need to be given the opportunity to discuss with professional staff.

It is possible to suggest that we must now move on from the plethora of research that identifies the flaws and contradictions in service response to CI, to a body of work that gives professional staff practical, empirical ways of addressing the uncertainty and need for continuity demonstrated in this thesis. Dialogue and open critique between the substantive bodies of disability and CI is stilted by the paradoxical hegemony of the voice of disabled activists who claim subjugation of the non-disabled voice as a tool for political victory against the social construction of disability. Concern with political correctness, and with theory that is so grounded in the data that it fails to enter into dialogue with the context in which it was born, leads

to findings that are sometimes framed within a political and ideological critique that locates itself within the failings of staff at ground level to address the needs of chronically ill people and their families. It is my personal belief that if chronically ill academics, or academics who find themselves in an informal care role, followed the lead of the disability rights movement, society might come closer to Mark's (1999) view of the world as 'contingently able bodied' in which society prepared actively for a world in which we will all experience chronic needs at some stage in our lives.

Conclusions

I realise now that prior to embarking on this study, I was blind to the depth of emotional and biographical experiences of my chronically ill patients and their families. My experiences as a hospice nurse and as a district nurse did little to prepare me for the complex mix of suffering, trauma, stress, hope and joy I witnessed during this research into the lived experience of chronic illness. My role as a researcher has given me a rare opportunity to leave my professional armoury behind, enabling me to embark on an emotional, spiritual and intellectual journey into the lives of my participants. The predominating memory is of people whose needs were categorised according to what was available, and of staff who met this incredible tension with an ability to see beyond the diagnosis. Despite organisational constraints that create and perpetuate uncertainty, the children and adults in this study wished me to witness their essences, encapsulated not in medicalised diagnostic parameters, but in life stories that showed who they were and how they coped with terrible illnesses, crippling uncertainty and the constant threat of early death. Similarly, the staff recognised the limits of their bio-physical capabilities and made amends for the failure of the curative promise that is western medicine, with friendship and mutuality.

This chapter has reflected on the contribution this study may make to understanding about the management of uncertainty. It is possible to suggest that the findings from this thesis are nothing more than that which nurses and other professional staff have long known intuitively about the need to know and support our patients, not just in the here and now, but along the whole trajectory in the

context of preserving relationships. The essence of this thesis 'Living with uncertainty' is a reminder that we all, patients, families and professional staff alike, are living and working in a world in which uncertainty cannot be eradicated. The future challenge for health, social care and education for people with chronic illnesses is to make that which is implicit and hidden into explicit, overt policies that acknowledge and address the realties of uncertain illness trajectories for hundreds of thousands of people in the United Kingdom every year.

Appendix 1.1 - CONSENT FORM (OBSERVATION)

At the University of Northumbria we are currently conducting a research study looking at the ways in which staff work together.

The study will focus on the care given by staff in this hospital to people who are admitted following a stroke. We would like to find people who have been affected by a stroke and spend some time watching what staff do for them on the ward. We will be looking at what kinds of staff come onto the ward and the type of things they do for people. We will also be asking staff questions to find out how staff think they can help people who have had strokes.

In order to undertake this research, I will spend up to ten hours every week for four weeks sitting with people and looking at what staff do for them. I will only remain by the bed with your permission.

All information given to us during the times of observation will be completely confidential, in other words, it will not be passed on to anyone else during the study. When we write our final report all personal details about the people that we spend time with will be removed from the report, so that everyone will be anonymous.

Thank you for taking the time to read this. If you would like to take part in this study, I would be grateful if you could sign in the space below. Please remember that you can change your mind at any time, and withdraw from the study if you want to.

I have read the information above, and have had the study explained to me in person. I would like to take part in this study, understanding that all information I give will be kept confidential and anonymous, and that I can withdraw from the study at any time.

Signed_____

Witnessed by_____

Date_____

Research conducted by:-Helen Routledge, Cheviot House, Institute of Health Sciences, University of Northumbria at Newcastle, Newcastle upon Tyne NE7 7XA .Tel 091 227 3022

Appendix 1.2 - CONSENT FORM (INTERVIEWS)

At the University of Northumbria we are currently conducting a research study looking at the ways in which staff work together.

The study will focus on the care given by staff in this hospital to people who are admitted following a stroke. We would like to find people who have been affected by a stroke and talk to them about their experience. We will also be asking staff questions to find out how staff think they can help people who have had strokes.
Before I start any interviews, you may notice me on your ward observing staff and looking at what they do for you.

In order to undertake my research I would like to talk to people about
a) what it is like for them to be ill and how the stroke has affected their lives
b) what they think their needs are
c) what the staff are doing for them on the ward

All information given to us in these interviews will be completely confidential, in other words, it will not be passed on to anyone else during the study. When we write our final report all personal details about the people that we interview will be removed from the report, so that everyone will be anonymous.

Thank you for taking the time to read this. If you would like to take part in this study, I would be grateful if you could sign in the space below. Please remember that you can change your mind at any time, and withdraw from the study if you want to.

I have read the information above, and have had the study explained to me in person. I would like to take part in this study, understanding that all information I give will be kept confidential and anonymous, and that I can withdraw from the study at any time.

Signed_____

Witnessed by_____

Date_____

Research conducted by:-Helen Routledge, Cheviot House, Institute of Health Sciences, University of Northumbria at Newcastle, Newcastle upon Tyne NE7 7XA .Tel 091 227 3022

Appendix 2.1 – Consent form for parents in phase two

Dear

Clients', informal carers', and staffs' perceptions of multiprofessional practice in hospitals and schools

Helen Routledge is a research student from the University of Northumbria, working on a project on children's and parents' views about how their needs are served by staff at ********** school. I am writing to ask your permission to involve your child in this project.

Helen will attend various classes at the school in order to get to know the staff and the children. Following this, she will be accompanying some of the children for a school day to learn about their activities (e.g. Physiotherapy). She will seek permission from the appropriate member of staff and the child before attending each class or activity. Obviously, some things (e.g. dressing clinic) are personal and private for the child and so she will not attend these activities.

Helen would also like to interview some of the parents about how they view the needs of their child and how best to meet those needs.

The information collected will only be shared with the school in an anonymous way so that you or your child cannot be identified. The information may also be shared in academic papers and conferences, again in an anonymous way.

I would be grateful if you would indicate on the slip below if you **do not** wish top take part on this project or if you **do not** wish for your child to take part in this project. If Helen receives no reply, she will assume you are willing to take part and may contact you by letter or phone to arrange further details. All further correspondence will be between you and Helen; if you decide not to take part, this information will not be passed on to the school and will not affect the care of your child in any way.

Thank you for taking the time to read this letter.

Yours sincerely
Xxxxxxxxxxxxxxxxxxxxxxxxx
(Head teacher)

YOUR FULL NAME: ----------

You do not wish to take part in the project

CHILD's NAME: ----------

You do not want your child to take part in the project

Appendix 2.2 – Observation schedule

Date	Time	Observed Interactions	Initial memo	Theoretical memo

Appendix 2.3 – Information sheet for children

Hello!

My name is Helen and I am a researcher at the University of Northumbria.
I am doing a project at your school about the ways that staff work to meet your needs.
I want to spend some time in classes and activities like physiotherapy to learn about the school, the staff and the children. I am not here to test anyone and I will only tell the school what I learn in an anonymised way. This means that I will not use your name when I am talking or writing about the things I learn.
You will see me around school for the next few months. Sometimes I will be joining in activities and sometimes I will just sit still and watch. I will sometimes write notes. I will not show these notes to the school and I will not write any names on the notes.
If you do not want me to stay in a class or an activity, please tell the teacher or you can tell me. If you don't want me to stay, you do not have to give a reason and I will not mind about this at all.
I want to talk to some children about their lives and what it is like to be at this school. I will pick names out of a hat to choose these children and I will ask them if they would like to be interviewed to tell me about their lives. It is okay to say yes or no to this.
I will use the things I see to understand ways of looking after children who have health problems or disabilities.

Thank you for reading this. I am looking forward to spending time at your school.

Helen Routledge

Appendix 3.1: Explanation sheet for photographs in phase two

PHOTO DIARY

Thank you for agreeing to take part in this project. I would like you to take photographs of things like:

People you know

Things you do

Places you go to

Anything that is important to you

You might include:

Your parents, your friends or staff at your school

Your favourite pet

Shopping trips or school visits

*** Please ask permission before you take a photograph of somebody.**

You can show them this sheet to explain what the photographs will be used for.

If you agree, we will talk about the photographs at our next interview. They will help me to understand what your life is all about. I hope this will help me to figure out ways of giving a good education and therapy to other children with disabilities or illnesses.
I will get the film developed and I will give you the photographs for you to keep. I will ask you to decide if I can use any of the photographs in some reports that I want to write about how children live with disabilities and illnesses. It is okay to say no or yes to this. I won't use your name or the name of your school in the reports.

Thank you very much for taking part. I really appreciate it.

Helen Routledge

Research Student

University of Northumbria

Appendix 4.1 - CONSENT FORM (INTERVIEWS) phase two

At the University of Northumbria we are currently conducting a research study looking at the ways in which staff work together to meet the needs of your child and your family.

The study will focus on the views of children and parents about their lives and their needs.

In order to undertake my research I would like to talk to people about
a) what they think their children's needs are and their family's needs
b) what the staff are doing for them at the special school
c) what their lives have been like in the past, and how they expect their lives to be in the future.

All information given to us in these interviews will be completely confidential, in other words, it will not be passed on to anyone else during the study. When we write our final report all personal details about the people that we interview will be removed from the report, so that everyone will be anonymous.

Thank you for taking the time to read this. If you would like to take part in this study, I would be grateful if you could sign in the space below. Please remember that you can change your mind at any time, and withdraw from the study if you want to.

I have read the information above, and have had the study explained to me in person. I would like to take part in this study, understanding that all information I give will be kept confidential and anonymous, and that I can withdraw from the study at any time.

Signed_____

Witnessed by_____

Date_____

Research conducted by:-Helen Routledge, Cheviot House, Institute of Health Sciences, University of Northumbria at Newcastle, Newcastle upon Tyne NE7 7XA .Tel 091 227 3022

Appendix 5.1: Letter attached to pilot questionnaire

Dear

Re: Clients', Carers', and Staffs' Perceptions of Multiprofessional Practice in Hospitals and Schools

Thank you very much for agreeing to pilot the above project. Attached to this letter is a short questionnaire which asks you to identify the needs of one of three children presented in theoretical case-studies. These case studies are based on interviews with children and their families and reflect issues that were important to these families. I would be very grateful if you will complete the questionnaire as soon as possible (no later than Friday, 22nd March) and return it in the enclosed envelope.

You will also find enclosed some questions regarding the questionnaire. Please read these questions before completing the questionnaire and answer them on completion of the questionnaire. Please do not hesitate to be critical - your views will help me to improve the questionnaire.

The information you provide will be treated confidentially and will only be used for the purpose of this study. Thank you again for your help.

Yours sincerely,

Clients', Carers', and Staffs' Perceptions of Multiprofessional Practice in Hospitals and Schools

1. How long did the questionnaire take to complete? _____

	Yes	No
2. Were the questions easy to understand?	☐	☐
3. Was there enough information in the case studies?	☐	☐
4. Did the presentation of the questionnaire make it easy to fill in?	☐	☐
5. Was it difficult to motivate yourself to complete the questionnaire?	☐	☐

6. Can you suggest ways of making the questionnaire more interesting or easier to fill in?

7. Do you have any other comments to make about this questionnaire?

Appendix 5.2 - Letter to questionnaire respondents in phase one

Dear colleague

Re: CLIENTS', INFORMAL CARERS' AND STAFFS' PERCEPTIONS OF MULTI-PROFESSIONAL PRACTICE IN HOSPITALS AND SCHOOLS

Thank you very much for agreeing to take part in the above project.

Attached to this letter is a short questionnaire which asks you to identify the needs of stroke patients presented in two case studies. Each case study has been derived from interviews with stroke patients and their carers and therefore reflects issues and concerns which the patients themselves identified. We feel that although this questionnaire will take time to fill in, it is extremely important to explore the issues identified by the patients with clinical staff such as you who are actually working with stroke patients. Therefore we would be very grateful if you could complete the questionnaire and return it to us in the enclosed prepaid envelope by .....

Your involvement in the study will be of great value and will inform decisions about the ongoing development of this research. A summary of the report of this work, which we anticipate will be completed by the end of summer 1995, will be sent to all participants.

It is important to state that whatever information you provide will be treated in the strictest confidence and will not be used for any purpose other than this study.

If you have any questions or would like to speak about any matter connected with this study please feel free to contact us.

May I take this opportunity to thank you for your help with this work.

Helen Routledge
Research Student
0191 227 3022

Institute of Health Sciences
University of Northumbria at Newcastle
NE7 7XA

APPENDIX 5.3 - Letter to professionals accompanying questionnaire in phase two

Dear ,

Re: Clients', Informal Carers', and Staffs' Perceptions of Multiprofessional Practice in Hospitals and Special Schools

I am contacting you with the full permission of the head teacher at the school where you work to ask if you are willing to take part in the above research project. The project, supported by the University of Northumbria, has involved observation and interviews with children with special needs and their families. It has the aim of eliciting and understanding the opinions and perceptions of these children and families about their needs. In order to place these opinions in context, we are now collecting data about staffs' perceptions of meeting needs so that we can understand the picture more fully. Your participation in this study will greatly help us to do so.

Attached to this letter is **a short questionnaire** which asks you to identify the needs of **one** of three children presented in theoretical case studies. These case studies are composite cases of a large number of children encountered during the research and therefore they reflect issues that were important to children and their families.

I would be very grateful if you can complete the questionnaire as soon as possible **(by ...).** A pilot study indicates that the questionnaire takes 15-25 minutes to complete fully; if you cannot spare that, I will be grateful for as little or as much information you can give. We appreciate how busy staff are at present but we feel that the study is of great importance and will enhance an understanding of your work.

The information you provide will be treated **confidentially** and will only be used for the purpose of this study. If you would like to receive a summary of the report of this work, please add your name and address (or your school address) to the enclosed slip and send it to us.

Thank you very much for any time you are able to spend on this.

Yours sincerely,

Helen Close

Appendix 6.1 – Example of observation notes

Taken from phase two

Observation	Code
Today, I watched while the children from class 4 went out to play in the small playground which is separate from the larger playground used by the older children. Playtime lasted for 30 minutes. It was a very warm day and the able bodied children all ran excitedly and noisily into the yard. Emma and Jade stopped running when they got halfway into the yard. Without speaking, they turned around and ran back inside the classroom. Each girl grabbed an arm of Kate's wheelchair and again running, they pushed her into the yard. Kate laughed and shouted 'Careful, I'll get another bone broke. Me mam will kill yous if I have to go back to hospital'. The girls then slowed down and carefully and gently wheeled Kate over to the bench where myself and Mrs C (class teacher) were sitting. E & J then sat down on the ground next to the wheelchair. Without any discussion, all 3 girls began to sing a pop song and did some complicated arm movements in time to the song. They invited Mrs C & myself to join in. At the same time, 4 other girls had started a game with a skipping rope and one of these girls shouted for E & J to join them. E & J looked anxiously at Kate. Kate smiled and said 'Eye, go on, I'll teach Miss the dance.' E replied 'We'll not be long'. Kate then proceeded to teach us the arm movements and the words of the song. After around 10 minutes, E & J ran back to Kate, breathlessly sat down and again without a word, began the pop song. Following this, we all sat in silence in the sunshine until Mrs C rang the bell to call the children back to class. This time J pushed Kate's wheelchair and gently manoeuvred it over the step into the classroom while E held Kate's hand.	**age segregation** **timed outdoor play** **energy/exercise** **unspoken decision** **unspoken shared care** **negotiating type of care** **consequences of physical illness** **protecting behaviour** **adult protection** **companionship** **unspoken communication** **shared culture** **exercise** **inclusive, public play** **conflict between friendships** **granting permission** **temporary parting** **child as teacher** **promised return** **unspoken communication** **caring role** **followed previous instructions** **physical expression of friendship**

Appendix 6.2 – Example of theoretical notes

Incident or data segment	Code	Theoretical note
Separate playgrounds	Age segregation	Thinking about how the school separates and deals organisationally with the children tells me a lot about the ethos within the school. Thinking about these children as little ones tells me what they are capable of understanding and doing, how I might expect them to act. Not sure what bearing this has on the interactions yet but will keep going.
30 min playtime	Timed outdoor play	Comparisons with mainstream school tell me that the school day in this special school has many similarities such as outdoor playtime. Scheduled activities such as physiotherapy and nursing care clearly make the school day different here. The head states that education is given precident over therapies. Need to focus my observations on these activities.
Excited, noisy behaviour	Exercise	I wonder if there are any classes where all the children are wheelchair users. What affect does this have on playtime?
Without speaking	Unspoken decision	The children seem to know each other so well that little discussion is necessary at times of decision making. There are other examples of this in the observation. Discussed this with deputy head - a lot of the kids stay in the same group for a long time and therefore know each other well. Are these friendships maintained outside of school and after leaving school at 18? Are they maintained during the long summer break?
Each girl grabbed the wheelchair	Unspoken shared care	This is evidence of care-taking. I think the girls do this because of a relationship based on mutual reciprocity. Other observation tells me that Kate is a very bright child and often assists and cares for her friends by helping with school work and by negotiating with staff if a

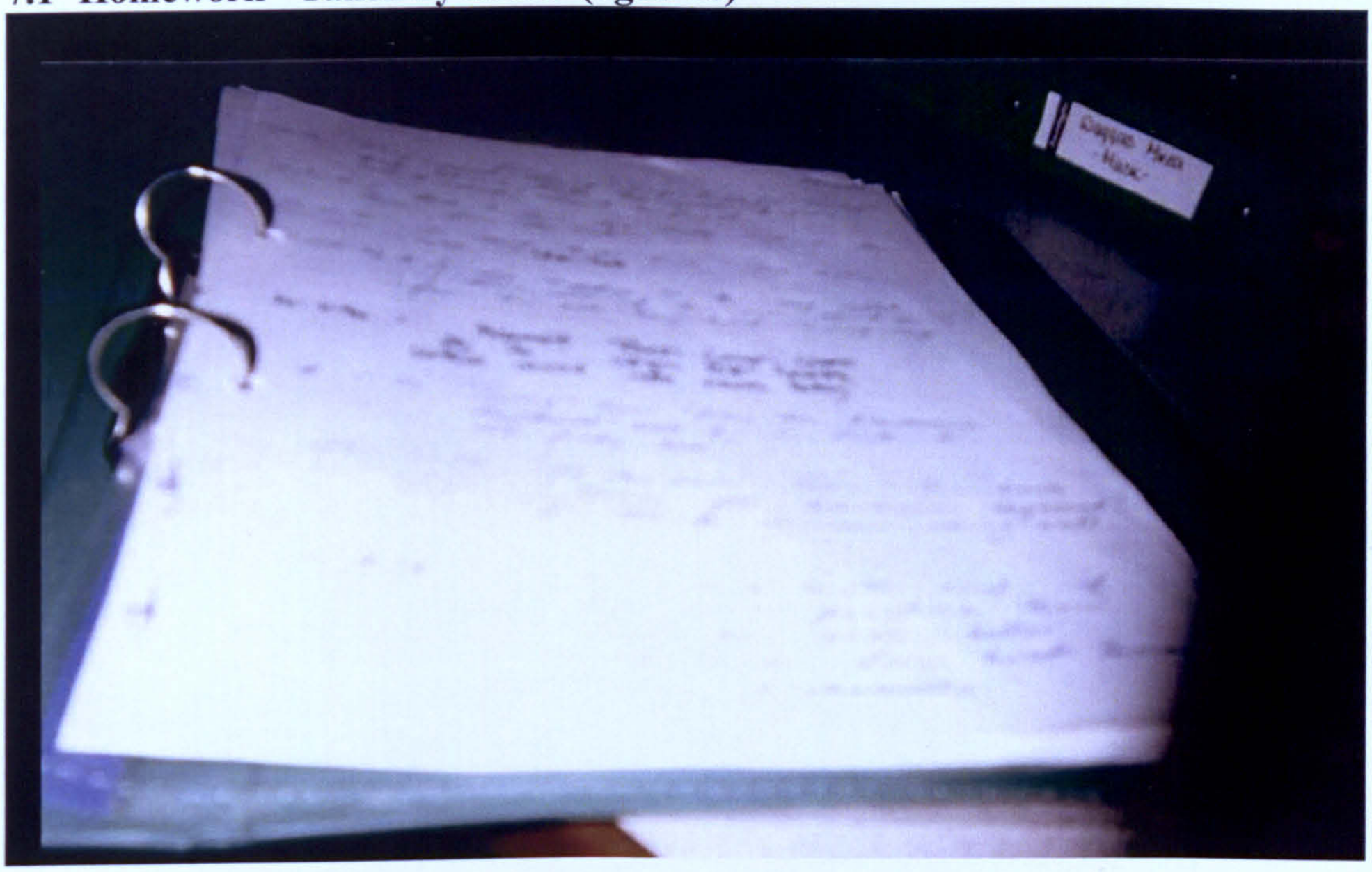
		friend is in trouble. This is a very important code to contribute to the category of mutual reciprocity.
Request to be careful due to brittle bone disease	Negotiating type of care	This places Kate as an active negotiator of her care rather than a passive recipient of the girls' kindness. Again, I think this contributes to mutual reciprocity. Is it about ground rules? What happens if the requests are ignored?
Broken bones. Parent's potential anger	Consequences of physical illness	Does Kate at this early age (7) understand the impact her illness has on her parents and family? Broken bones are a routine event for Kate. How does this affect the coping mechanisms of the family? Does the frequency make it easier or harder to cope with? The girls were well practised at using a wheelchair and had obviously pushed Kate many times. This was about keeping Kate safe and free from injury.
Kate was slowly and gently wheeled	Protective behaviour	Kate's entreaty to be careful led to her being positioned next to the teacher. Do the children see the school as a place of safety from the outside world? Is this any different from a main stream school? Certainly, I have so far never heard a member of staff raise their voices at the children. Is this a feature of special schools? Is it a feature of any schools fortunate enough to have a small intake?
Positioned Kate next to teacher	Adult protection	This is linked with mutual reciprocity and friendship.
Girls all sat together	Companionship	Again, this theme about familiarity and closeness shows itself.
Without discussion, a song was begun	Unspoken communication	This is very important to the children. The latest popular culture is a constant topic of conversation: clothes, pop stars, music, videos, TV programmes, dance moves, magazines. I wonder if the kids are aware of ways in which disability is portrayed in pop culture. Is this important? Why? Again linked with the theme of mutual reciprocity – I have often seen the
Girls sang a pop song	Shared culture	

		most physically disabled kids trade knowledge & info on pop, videos, copies of music tapes, magazines with more able-bodied kids in return for favours such as carrying bags to class and pushing a wheelchair. Sometimes this trade off is an explicit agreement, sometimes more subtle. Need to discuss this in interviews.
Arm movements	Exercise	Kate is recovering from another broken arm. This exercise is physiotherapy willingly undertaken! The dividing line between play and physical therapy is very blurred for children. I need to spend time observing therapy sessions to check this out further.
Adults invited to join in song	Inclusive, public play	The girls showed closeness and shared elements of the friendship, But were willing to include adults in their play. Do they have secret, private play? How would I ever gain access to this? What would be the benefit of this? The lit points to the lack of privacy afforded to disabled people. Is including adults an expression of this? How does this compare with able-bodied children?
Girls invited to play able-bodied game	Conflict between friendships	A tension seems to exist between caring for the disabled child and wishing to play able-bodied games. It will be pertinent to see how far the kids can articulate this tension during interviews.
Kate gives permission to go and play	Granting permission	The children look to Kate to make decisions and give instructions. This carries over into other observed interactions, particularly in class where Kate often takes on the role of teaching assistant. What qualities make this possible? Is this a trait encouraged by the school. Emotional strength and intelligence are certainly prized by teachers. What affects do these qualities have in later life? What impact do they have on coping with disability? Again, this seems to be about friendship, safety, and care-taking. Not sure how they are

		all linked.
Emma reassures Kate that she will return soon	Temporary parting	Again, this theme may prove important as in some childrens' leadership skills. I'm starting to relate this to disability lit about how disabled kids are not given the chance to be kids in terms of expectations about their behaviour and abilities (not allowed to be naughty or deviant). Are these kids expected to have adult traits because of perceptions of disability and coping? Some lit points to fact that verbal and communication skills are more highly developed in some kids who have spent long time in hosp and have therefore had lots of one-to-one time with parents and adult staff members. Is this a factor here?
Kate taught adults song and dance	Child as teacher	Again, I think this is about friendship and mutual reciprocity.
Girls returned to Kate	Promised return	I often see the children performing kind acts and this is something the school actively encourages. Don't know what significance yet,
Jade pushed Kate's chair	Caring role	Similar debate to permission granting and being 'good'.
Jade was careful and gentle	Followed instructions	The lit & my own experience is that little girls of all physical abilities show physical affection to adults and peers alike. Kids here need to be more aware of physical safety in terms of not damaging fragile bones and bodies. Again linked with familiarity, caring role, mutual reciprocity.
Emma held Kate's hand	Physical expression of friendship	

APPENDIX 7: PHOTOGRAPHS TAKEN BY CHILDREN

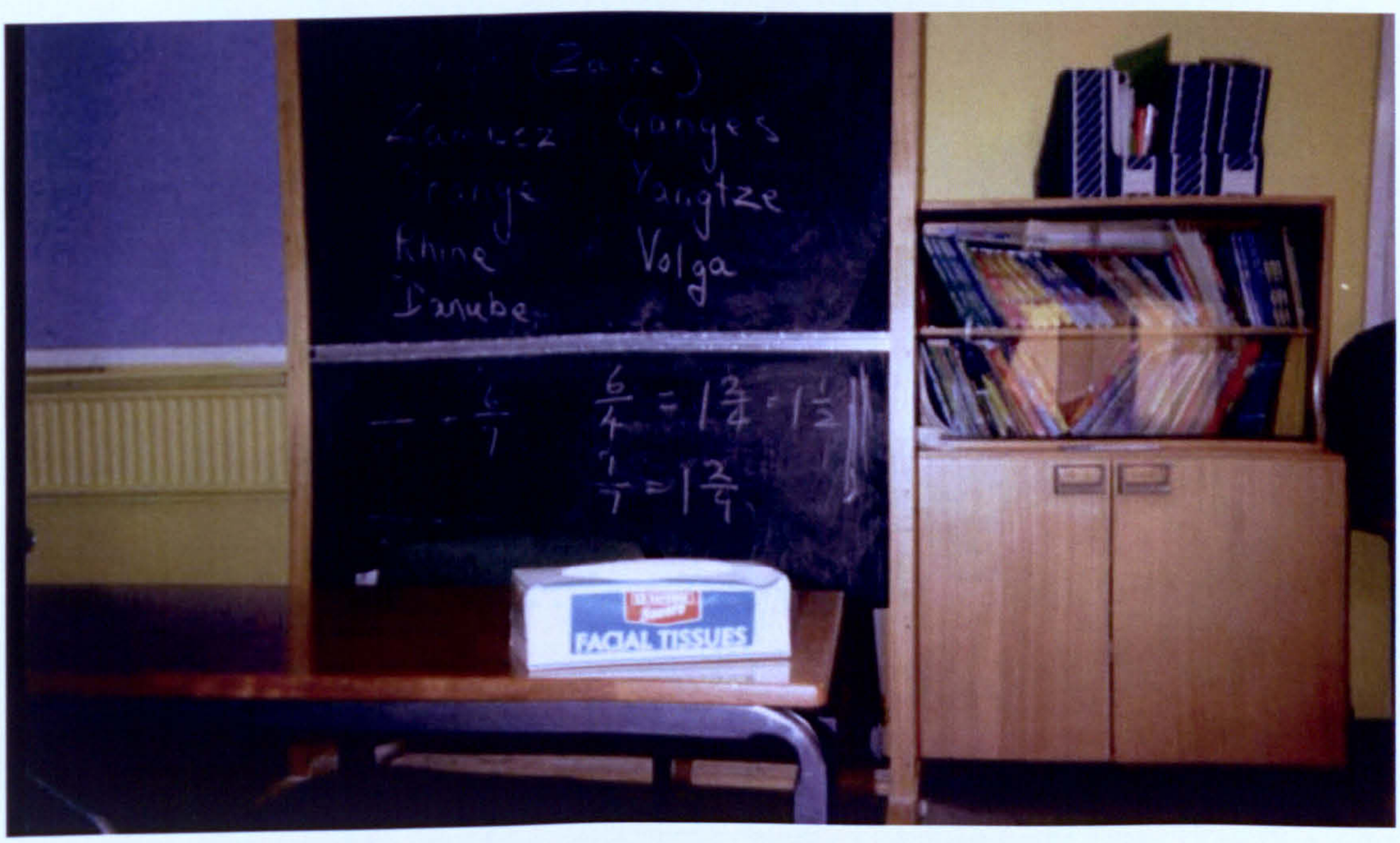
7.1 'Homework' Taken by Hanif (aged 16)



7.2 'My room' Taken by Jake (aged 11)

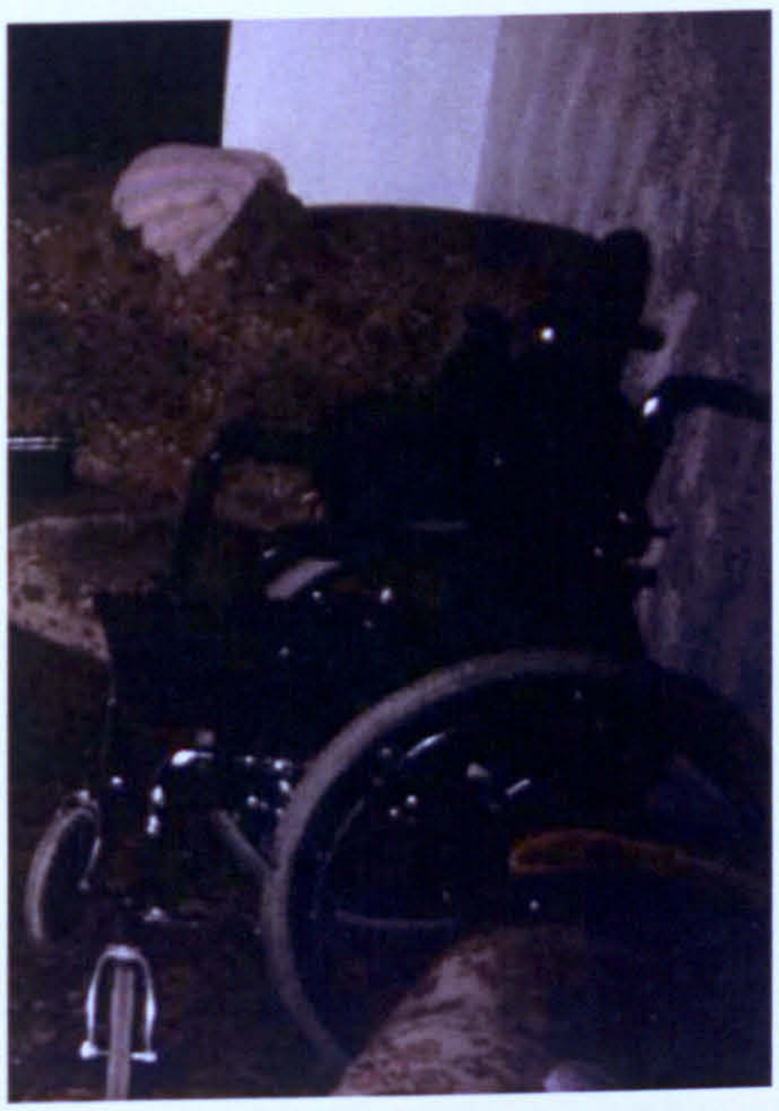
7.3 'Playing hockey in the school hall' (Taken by Peter, aged 14)

7.4 ' My classroom' Taken by Rebecca (Aged 15)

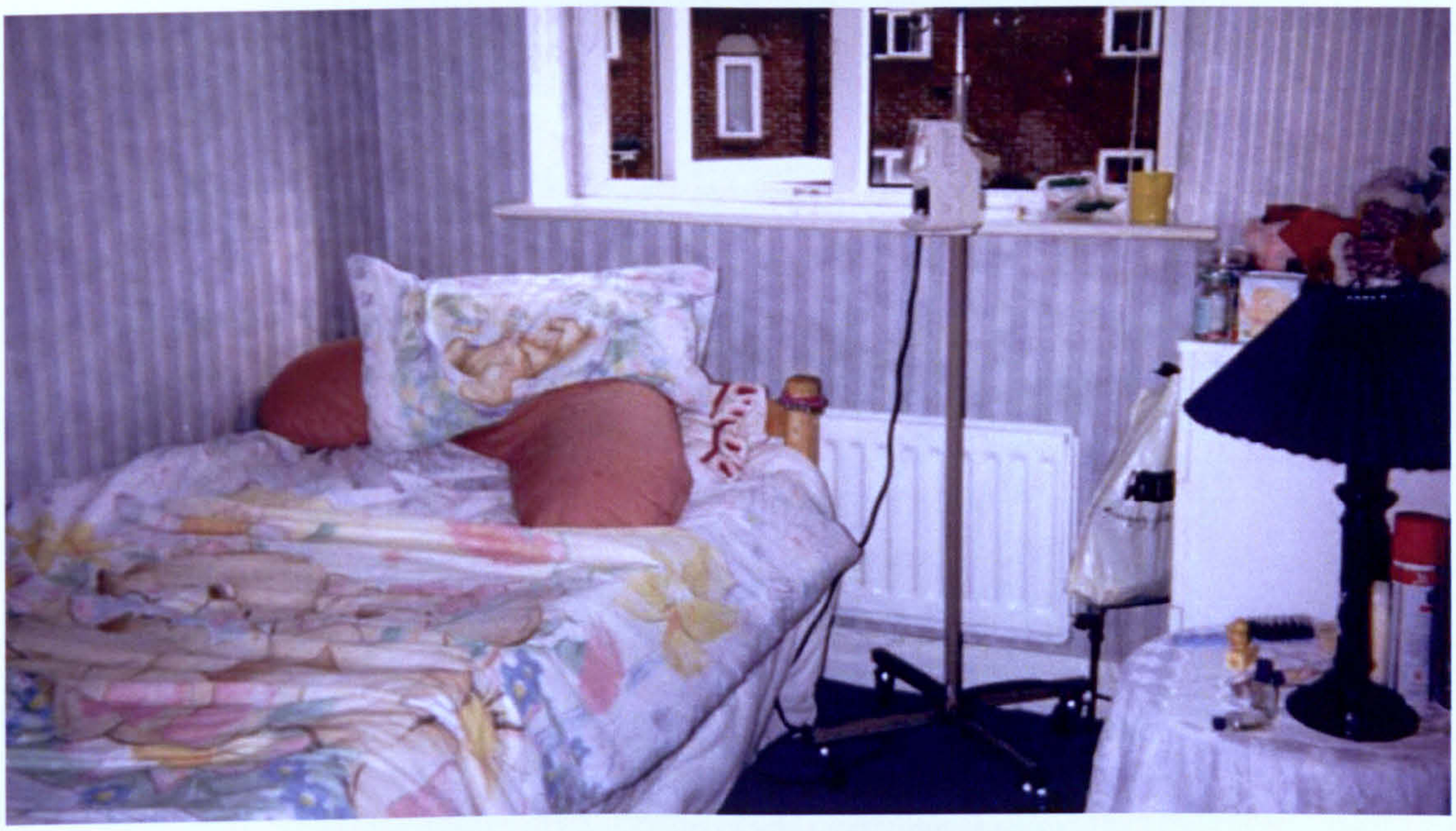


7.5 'Physio' Taken by Simon (aged 15)

7.6 'My chair' taken by Kate (aged 8)



7.7 My Bedroom (by Monica, aged 11)



Read the following case study and answer the questions below.

Mr A is an 85 year old man who lives with his disabled wife in a terraced bungalow. He has suffered a stroke and has been transferred today from casualty to the District General Hospital in your geographic area of practice. Mr A's children live abroad. He had previously cared for his wife until his admission to hospital. She is currently being cared for by a neighbour. Mr A is not able to speak but is able to understand and act on verbal instructions. He is able to eat and drink and is fully continent. He has little movement in his right leg and no movement in his right arm. He is physically unable to wash and dress. This is his first stroke.

AIMS AND INFORMATION

We have given you a small amount of information about Mr A in the case study. These questions focus on the aims you might have in this case and the information that you might need to make decisions about Mr A.

IMMEDIATE AIMS

i) With respect to your professional role, what would be your immediate aims in this case?	**ii) Having read the case study, what additional information about this case would you seek today? How would you get this information?**

LONGER TERM AIMS

iii) What would be your long term aims in this case?	**iv) What information about this case study would you need to plan for the future? How would you get this information?**

SECTION A: **PATIENT REFERRAL**

This section focuses on staff who might become involved with this case.
Please answer the questions using the following codes, where appropriate:

A: *Chiropodist*	***D:*** *Occupational Therapist*	***G:*** *Speech Therapist*
B: *Consultant Physician*	***E:*** *Physiotherapist*	***H:*** *Qualified Nurse*
C: *Dietician*	***F:*** *Social Worker*	***I:*** *Other (please specify)*

v) Who would normally tell you that this case needs your professional input?

Tick more than one box if necessary and specify using letters given above

1. Another Professional ☐ _____

2. Casualty or other Department ☐ _____

3. G.P. ☐

4. Community Care Team ☐

5. Other ☐ *Please specify* _____

vi) Who would you normally refer this patient to:	**vii) Please give reasons why you would make these referrals.**
Tick more than one box if necessary **1. Another Professional** *(please specify using letter(s) given above)* ☐ _____ **2. Casualty or other Department** *(please specify)* ☐ _____ **3. G.P.** ☐ **4. Community Care Team** ☐	**1:** _____ **2:** _____ **3:** _____ **4.** _____ **5:** _____

5. Other *(please specify)* _____	

SECTION B

Read the following case study and answer the questions below.

Mr B is a 59 year old mechanic who lives with his wife and daughter in a council cottage. He has been a patient in a District General Hospital in your geographical area of practice since suffering a stroke four weeks ago. His wife travels from her job as a shop assistant every afternoon to visit him and repeatedly asks staff whether he will recover and whether she will have to give up her job in order to care for her husband. Mr B has some movement in his left leg but not in his left arm. He has slurred speech and has full awareness of his needs and surroundings. He has difficulty swallowing fluids and solids. He is incontinent of faeces and urine and finds it physically difficult to wash and dress. Mr B sleeps for three to four hours every night and two to three hours every afternoon. When spoken to, he weeps and groans and is unable to express any reason for crying. He has had two mild heart attacks in the past five years and has had tablet controlled diabetes for the past twenty years. This is his first stroke.

AIMS AND INFORMATION:

Again, we have given you a small amount of information about Mr B in the case study. These questions focus on the aims you might have in this case and the information you might need to make decisions about Mr B.

IMMEDIATE AIMS

i) With respect to your professional role, what would be your immediate aims in this case?	**ii) Having read the case study, what additional information about this case would you seek today? How would you get this information?**

LONGER TERM AIMS

iii) What would be your long term aims in this case?	**iv) What information about this case study would you need to plan for the future? How would you get this information?**

SECTION B **PATIENT REFERRAL**

This section focuses on staff who might become involved with this case.
Please answer the questions using the following codes, where appropriate:

***A:** Chiropodist*	***D:** Occupational Therapist*	***G:** Speech Therapist*
***B:** Consultant Physician*	***E:** Physiotherapist*	***H:** Qualified Nurse*
***C:** Dietician*	***F:** Social Worker*	***I:** Other (please specify)*

v) Who would normally tell you that this case needs your professional input?

Tick more than one box if necessary and specify using letters given above

1. Another Professional ☐ ——

2. Casualty or other Department ☐ ——

3. G.P. ☐

4. Community Care Team ☐

5. Other *Please specify* _____

vi) Who would you normally refer this patient to:	**vii) Please give reasons why you would make these referrals.**
Tick more than one box if necessary	
1. Another Professional *(please specify using letter(s) given above)* ☐ _____	**1:** _____
	2: _____
2. Casualty or other Department	**3:** _____

(please specify)	☐	_____	4. _____
3. G.P.	☐		5: _____
4. Community Care Team	☐		
5. Other *(please specify)*	☐	_____	

SECTION C

Read the following case study and answer the questions below:

Mrs C is a 74 year old widow who lives alone in a warden controlled flat. Ten weeks ago she suffered a stroke and was admitted to the District General Hospital in your geographical area of practice. She has one son and one daughter who both live near her. Her daughter suffers frequent epileptic fits but visits when she is able. Her son visits daily. Mrs C had a stroke five years ago which caused her to have slurred speech. She is able to walk short distances with the aid of a zimmer frame. She is able to eat and drink and is fully continent. She is able to wash and dress independently. She continues to have slurred speech. She is fully aware of her needs and surroundings. Mrs C cries several times a day and states that she is frightened to go home. She asks several times daily whether she will get any better and whether she will have another stroke.

AIMS AND INFORMATION

Again, we have given you a small amount of information about Mrs C in the case study. These questions focus on the aims you might have in this case and the information you might need to make decisions about Mrs C.

IMMEDIATE AIMS

i) With respect to your professional role, what would be your immediate aims in this case?	**ii) Having read the case study, what additional information about this case would you seek today? How would you get this information?**

LONGER TERM AIMS

iii) What would be your long term aims in this case?	iv) What information about this case study would you need to plan for the future? How would you get this information?

SECTION C **PATIENT REFERRAL**

This section focuses on staff who might become involved with this case.
Please answer the questions using the following codes, where appropriate:

A: *Chiropodist*
B: *Consultant Physician*
C: *Dietician*
D: *Occupational Therapist*
E: *Physiotherapist*
F: *Social Worker*
G: *Speech Therapist*
H: *Qualified Nurse*
I: *Other (please specify)*

v) Who would normally tell you that this case needs your professional input?

Tick more than one box if necessary and specify using letters given above

1. Another Professional ☐ _____

2. Casualty or other Department ☐ _____

3. G.P. ☐

4. Community Care Team ☐

5. Other ☐ *Please specify* _____

vi) Who would you normally refer this patient to:	vii) Please give reasons why you would make these referrals.

Tick more than one box if necessary

1. Another Professional
(please specify using letter(s) given above) ☐ _____

2. Casualty or other Department
(please specify) ☐ _____

3. G.P. ☐

4. Community Care Team ☐

5. Other
(please specify) ☐ _____

1: _____

2: _____

3: _____

4. _____

5: _____

SECTION D *PATIENT NEEDS*

In this section you are asked to look back at the case studies and answer the following questions on specific areas of client needs. Please give as much detail as possible when answering these questions.

CASE STUDY A

i) Based on your professional experiences, can you indicate how long After Mr A's stroke might he be discharged home?

Tick one box

Under 1 week	☐	2 months	☐	5 months	☐
3 weeks	☐	3 months	☐	6 months	☐
1 month	☐	4 months	☐	Never	☐

ii) Based on your professional experience, does a first stroke (like that experienced by Mr A) indicate an Increased risk of subsequent strokes?

Yes ☐ No ☐

iii) What information would you normally give to clients/ relatives about this?

_____

_____

_____

CASE STUDY B

i) From your experience, how would you normally involve Mr B's wife in planning for Mr B's discharge from hospital?

CASE STUDY C

i) Given Mrs C's concerns about going home, can you suggest options that might be available to her after discharge from hospital?	ii) How might you answer Mrs C's questions about her prognosis?

Appendix 8.2- Questionnaire for professionals working in hospitals in phase one

University of Northumbria at Newcastle

Clients', Carers', and Staffs' Perceptions of Multiprofessional Practice in Hospitals and Schools

All instructions for this questionnaire are given in italics

Full instructions are given alongside the questions. Most questions ask you to write your answers as fully as possible. Some ask you to enter a letter using the codes given below, or to tick a box or boxes.

A: Casualty (or other dept)

B: Chiropodist

C: Consultant physician

D: Dietician

E: Occupational Therapist

F: Physiotherapist

G: Primary Health Care Team

H: Medical Social Worker

I: Speech Therapist

J: Qualified Nurse

K: Voluntary Agency (Please specify)

L: Other (please specify)

If you wish to use extra paper to add any more information, please indicate on each sheet the relevant question number and section and attach it securely to this form.

If you have any queries regarding this questionnaire, please contact us at the address given below:

Helen Routledge
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Susan Procter
Professor of Nursing
Tel: 0191 227 4983

Colin Biott
Reader in Education
Tel: 0191 227 3813

Faculty of Health, Social Work and Education
University of Northumbria at Newcastle
Coach Lane Campus
Newcastle upon Tyne
NE7 7XA

Thank you for your participation

Background Information

The following questions ask for information about you which will only be used for the purpose of this research project. All answers you give in this questionnaire will be treated confidentially and will be anonymised in the final report.

1. Are you: Female ☐ Male ☐

2. Your age: Less than 25 ☐ 46 - 55 ☐

25 - 35 ☐ More than 55 ☐

36 - 45 ☐

3. Your job title and grade / position: _____

4. In what year did you qualify as a practitioner? _____

5. How many years have you worked in your current role?

Less than 1 year ☐ 16 - 25 years ☐

1 - 5 years ☐ More than 25 years ☐

6 - 15 years ☐

6. Does your place of work have a specialised area for stroke patients?

Yes ☐ No ☐

7. If you answered yes to question 6, please describe this specialised area.

_____

_____

_____

CASE STUDY ONE

The following case study describes a man who has suffered a stroke. Please read the case study and imagine that the man has been transferred from casualty at 8.30 this morning to a ward in the hospital where you work or are attached to.

Mr T is a 59 year old mechanic who lives with his wife and daughter in a council cottage. His wife works part-time as a shop assistant. Mr T has some movement in his left leg but not in his left arm. He has slurred speech and has full awareness of his needs and surroundings. He has difficulty swallowing fluids and solids. He is incontinence of faeces and urine and finds it physically difficult to wash and dress. When spoken to, Mr T weeps and groans and is unable to express any reason for crying. He has had two mild heart attacks in the past five years and has had tablet controlled diabetes for the past twenty years. This is his first stroke.

SECTION 1.A

This section focuses on staff who might become involved with this case.

1) With respect to your professional role, when would you expect to become involved with this case?

Please tick one box

Today ☐ In 2 weeks ☐ In 2 months ☐

In 1 week ☐ In 1 month ☐ Other ☐

(please specify)

_____

Please use the codes given on p[age one to answer questions 2,3 and 4

2) Who (e.g. Nurse, social worker) would normally refer this case to you, or tell you this case needs your professional input?

_____ _____ _____ _____ _____ _____ _____

3) Who would you normally report your input to?

_____ _____ _____ _____ _____ _____ _____

4) How would you do this? Please tick more than one box

Ward round ☐ Medical notes ☐ Informal conversation ☐

Team meeting ☐ Nursing notes ☐ Departmental notes ☐

Written report ☐ other (specify) ☐

SECTION 1.B

The following questions focus on the aims you would have in this case and the information you would need to make decisions about Mr T.

5) You have told us in question 1 when you would become involved with this case. Imagine that you have reached this point where you have just become involved with the case and answer the questions in the boxes below.

IMMEDIATE AIMS

5.1) With respect to your professional role, what would be your immediate aims in this case?

5.2) What information about this case would you seek at your first visit with Mr T? How would you get this information?

LONG TERM AIMS

5.3) Based on your professional experience, can you indicate how long after Mr T's stroke might he be discharged home?

Please tick one box

Under 1 week	☐	2 months	☐	5 months	☐
1 – 3 weeks	☐	3 months	☐	6 months	☐
1 month	☐	4 months	☐	never	☐

5.4) What would be your long term aims in this case?

5.5) What information about this case study would you need in order to plan for the future? How would you get this information?

CASE STUDY TWO

The next case study describes the story of a woman who has suffered a second stroke eight weeks ago. Please read the case study and imagine the woman was admitted eight weeks ago to a ward in the hospital where you work or are attached to.

Mrs f. is a 74 year old widow who lives alone in a warden controlled flat. She has one son and one daughter who both live near her. Her daughter suffers frequent epileptic fits but visits when she is able. Her son visits daily. Mrs F. had a stroke five years ago which causes her to have slurred speech. Following her second stroke, she is able to walk short distances with the aid of a zimmer frame. Sheis able to eat and drink and is fully continent. She is able to wash and dress independently. She is fully aware of her needs and surroundings. Mrs F. cried several times a day and states that she is frightened to go home. She asks several times daily whether she will get any better and whether she will have another stroke.

SECTION 2.A

This section focuses on staff who would become involved with this case.

2) With respect to your professional role, when would you expect to become, or to have become, involved with this case? Please tick one box

Immediately after admission ☐

2 weeks after admission ☐

2 months after admission ☐

1 week after admission ☐

1 month after admission ☐

Other (please specify) ☐

AIMS OF CARE

2) Please list all the staff you would normally expect to come into contact with Mrs F. in the eight weeks she has spent in hospital	**3) Please outline what contribution each group of staff would make.**

SECTION 2.B

This section focuses on the aims you would have in this case and on specific areas of client needs.

1) **With respect to your professional role, what would be your aims in this case over the next week?**

2) **Given Mrs F's concerns about going home, can you suggest options available to her?**

3) **How might you answer Mrs F's questions about her prognosis?**

4) From your experience, how would you normally involve Mrs F's family in planning for her future?

Thank you very much for your contribution

Appendix 8.3- Questionnaire for professionals working in special education in phase two

University of Northumbria at Newcastle

Clients', Carers', and Staffs' Perceptions of Multiprofessional Practice in Hospitals and Schools

All instructions for this questionnaire are given in italics

Full instructions are given alongside the questions. Most questions ask you to write your answers as fully as possible. Some ask you to enter a letter using the codes given below, or to tick a box or boxes.

A: Class teacher

B: Consultant Paediatrician

C: Dietician

D: District Nurse

E: Educational Psychologist

F: G.P.

G: Head Teacher / Deputy Head

H: Occupational Therapist

I: Physiotherapist

J: School Doctor

K: School Nurse

L: Social Worker

M: Specialist Teacher

N: Speech and Language Therapist

O: Teaching Auxiliary

P: Voluntary Agency; please specify

Q: Other; please specify

If you wish to use extra paper to add any more information, please indicate on each sheet the relevant question number and section and attach it securely to this form.

If you have any queries regarding this questionnaire, please contact us at the address given below:

Helen Close
Research Student
Tel: 0191 227 3022

Susan Procter
Professor of Nursing
Tel: 0191 227 4983

Colin Biott
Reader in Education
Tel: 0191 227 3813

Faculty of Health, Social Work and Education
University of Northumbria at Newcastle
Coach Lane Campus
Newcastle upon Tyne NE7 7XA

Background Information

The following questions ask for information about you which will only be used for the purpose of this research project. All answers you give in this questionnaire will be treated confidentially and will be anonymised in the final report.

1. Are you: Female ☐ Male ☐

2. Your age: Less than 25 ☐ 46 - 55 ☐

25 - 35 ☐ More than 55 ☐

36 - 45 ☐

3. Your job title and grade / position: _____

4. In what year did you qualify as a practitioner? _____

5. How many years have you worked in your current role?

Less than 1 year ☐ 16 - 25 years ☐

1 - 5 years ☐ More than 25 years ☐

6 - 15 years ☐

6. Please describe the school / unit/ centre in which you come into contact with children with special needs.

_____

_____

_____

CASE STUDIES

The following case studies describe 3 children with varying ages and problems. Please read all 3 and then decide which case study you would like to answer questions about.

CASE STUDY A

Simon is a 13 year old boy who lives with his parents and his 5 year old sister in a terraced council house. Simon attends a special school near his home. Simon's father suffers from arthritis and is partially deaf. He does not work but takes the children to and from school and does the house work. Simon's mother works full-time in a bank.

Simon has cerebral palsy and is partially deaf. He has mild learning difficulties and he finds it difficult to concentrate on a task for more than five minutes. Simon is often aggressive and uses his electric wheelchair to bang into, and wound, other children and staff. He has control over his bladder and bowels but is occasionally incontinent. He has limited control of his hands and uses a communication keyboard to overcome his speech difficulties.

CASE STUDY B

Kate is a 16 year old girl who lives with her mother and two brothers in a semi-detached house. Kate attends a special school thirty miles from her home. Kate's parents are divorced and her father does not keep in contact with the family. Her mother works full-time as a shop assistant.

Kate has spina bifida. She has a urinary catheter and is faecally incontinent. She has mild learning difficulties and enjoys cookery. Kate can walk unaided with a slow, clumsy gait but prefers to use a self-propelling wheelchair because she feels she has more freedom of movement in the chair. At school, Kate has begun spending a lot of time with an 18 year boy who has been sexually active in the past. Kate is articulate and attentive and particularly enjoys maths and science.

CASE STUDY C

Anna is an 7 year old girl who lives with her parents and 5 brothers and sisters above their grocery store. Anna and her family came to live in Britain 6 years ago and regularly visit their family in Pakistan. Anna attends a main stream school near her home.

Anna is partially sighted and has asthma. She is very quiet and attentive in class and finds it difficult to make friends. She gets very upset if another child is disruptive or if she hears shouting. She frequently touches her genital area during lessons. Anna has been in hospital several times for treatment of her asthma and for correction of a congenital squint.

Please indicate which case study you would like to answer questions about:

A: ☐ **B:** ☐ **C:** ☐

Whichever case study you have chosen, imagine that the child is in a school where you work or are attached to.

Section 1:
These questions focus on staff who might be involved with the child and his/ her family. Please use the codes given on the front page to answer questions 1,2 and 4.

1. Who would normally have referred this child to you, or told you that this case needs your professional input? _____ _____ _____ _____ _____ _____ _____ _____ _____ _____

2. Who would you normally report your input to/ discuss your input with?

_____ _____ _____ _____ _____ _____ _____ _____ _____ _____

3. How would you do this?
Please tick more than one box

Meeting with staff from other professional groups ☐

Written report ☐

Meeting with staff from same professional group ☐

Informal conversation ☐

Other (please specify) _____

4. Aims of care

a) Using the codes on page one, please list all staff you would expect to come into contact with the child and / or family at home and /or at school.	**b) Please outline what contribution you would expect each group of staff to make.**

Section 2

The following questions focus on the aims you would have in this case and the information you would need to make decisions about the child and his / her family.

Immediate aims

5. With respect to your professional role, what would be your immediate aims in this case?

6. What more would you need to know about this case?	**7. How would you get this information?**

Section 3

Long term aims

8. What would be your long term aims in this case?

9. What more would you need to know in order to plan for the future?	**10. How would you get this information?**

Section 4

These questions ask about specific issues that might arise from each case study. Please answer the appropriate questions for the case study you chose.

CASE STUDY A:

11. With regard to your professional role, how would official policy guidelines advise you to deal with Simon's aggression?

12. In practice, what might you do to deal with his behaviour?

13. Simon's father has a disability. Would this be something you would consider when giving input into Simon's case? If so, how?

CASE STUDY B:

14. With regard to your professional role, how do official policy guidelines advise you to deal with Kate's growing sexual awareness?

15. In practice, how might you deal with this?

16. Kate prefers to use a wheelchair rather than to walk with sticks. What would be your advice to Kate and her parents about this?

CASE STUDY C:

17. With regard to your professional role, how do official policy guidelines advise you to deal with Anna's masturbation?

18. In practice, how might you deal with this?

19. Anna finds it difficult to make friends. Would you regard friendships as something to consider in the organisation of your work? If so, what might you do to facilitate friendships for Anna?

Thank you very much for taking the time to fill this questionnaire in.

Please send it to us using the enclosed pre-paid envelope

Appendix 9.1 – Example of a theoretical memo

Making comparisons - 'being better off than others'
Taken from Observation period 4 with Kate. Phase 2
*I ask myself, what is going on here? Observation shows kids seem to choose friendships with children who share either the same diagnostic category or a similar level of physical disability: wheelchair users tend to play together, as do crutch users; kids with MND play together. During observation, I hear comments based on comparisons such as 'look at *** he is much worse than me. He has blue lips' 'There are 10 boys like me but I'm not as bad as *****'. 'I'd hate to be bad like******* cos then I couldn't go swimming' 'You know ***? She's got wriggled bones. I haven't got anything wrong with me.' Discussion with staff show that although they recognise that comparisons with others occurs, they do not encourage or acknowledge it. They are careful never to discuss a child's diagnosis or disability in earshot of the children and do so because they feel the ethos of the school is to treat each child in terms of their abilities not their disabilities. How does this prepare children for adult life? Does it constitute a denial of disability and if so what affect does this have on a child's self-perception? Do parents use the same tactics (maybe I should do joint interviews with parent and child to check this out)? It seems that making comparisons with others is an important code just as it is in the hospital phase. Hopefully the questionnaire and interview phase will tell me more about what happens if comparisons reveal that you are the most badly affected by a disability or the most ill among your peer group. Are there any positives to be had from being the 'most ill' or the 'worst affected' or are the consequences all seen as negative? Why do children want to make comparisons? Do they only do so in school or also in the home environment or in hospital during acute episodes? Are there any children who do not fit easily into a group either because they are comparatively fit or very ill?*

Appendix 9.2 - Codes taken from phase one

1. Informal care
Being a burden
Helpseeking
Taking responsibility
Sharing tasks
Extended family
Children as carers
Friendships
Role negotiation
Mutual exchange

2. Feelings
Anxiety
Mistrust
Anger
Uncertainty
Loss of control
Boredom
Acceptance
Confidence
Hostility
Denial
Hope
Hostility
Fear

3. Needs
Physical and medical
Emotional and social
Information
Financial

4. Relationships
Friendships
Sexual relationships
Dependency
Mutual reciprocity
Role negotiation
Power
Obligation

5. Routine
Formal care
Therapy
Power and control
Comparisons with others
Daily events
Special events

Crisis
Resource competition
Free-time

6. Information
Information disclosure
Information seeking
Conflicting information
Sources of information
Uncertainty
Role negotiation
Power
Information deficit
White lies
Playing the game
Communication
Pacing information giving
Diagnosis

7. Coping
Normalisation
Time-out
Shared care

8. Achievement
Physical milestones
Emotional coping
Role negotiation
Adapting to circumstance
Resources
Progress
Comparisons with others
Expectations
Goal setting
Acute
Chronic
Prognosis

Appendix 9.3 - Codes from phase two

1. Information
Information seeking
Conflicting information
Disagreement
Role negotiation
Power
Information leading to action
2. Parent relationships
Hostility
Disputing
Challenging knowledge and power
Parental compliance
Professional compliance
Adaptation
Role negotiation
Mutual reciprocity
Acknowledgement of role
Conflict
Agreement
Sharing
Manipulation
Crisis
Comparisons
Marital breakdown
Shared experiences
Comparisons
Mutual support
Sense of 'specialness'
3. Impact of aids and equipment
Strength
Power
Mobility
Bullying
Freedom
Restrictions
Sleep
Home environment
Goal setting
4. Achievement
Comparisons with others
Diagnosis
Prognosis
Progress

Mobility
Education
Exams
Manipulation
Role negotiation

5. Child relationships
Friendships
Mutual reciprocity
Companionship
Caring role
Shared culture
Leadership
Closeness
Role negotiation
Adaptation to resources
Adaptation to situation
Privacy
Negotiating care
Control
Illness management
Siblings
Parents
Autonomy
Independence
Child as teacher
Conflict
Compliance
Bullying
Social inclusion
Social exclusion
Comparisons
Shared experiences
Achievement

6. Feelings
Denial
Disbelief
Sorrow
Anger
Love
Confidence
Fear
Acceptance

Appendix 10 - Characteristics of the patients, children, families and formal carers who took part in the study

Phase one

The patients and their families

There were 12 patients (6 male and 6 female) in phase one, all of whom had suffered an acute stroke requiring hospital admission. At the time of interviewing, 8 patients were over 70, 3 were between 59 – 70, and 1 was 42 years of age. The focus of this study was on the triad relationship between patients, families and formal carers. It was therefore important to map the family membership of participants. The family membership and living arrangements are shown in table 6. This indicates that the majority of patients were in nuclear families with a spouse and children. 4 people were widowed or unmarried and lived alone. 1 year following the stroke, only 4 people were able to return home to live with their spouse.

Family structure	Number	Living arrangements pre-stroke	Number	Living arrangements 1 year post-stroke	Number
Married	8	With spouse	4	With spouse	3
Single	1	With spouse & children	3	Sheltered accommodation	3
Widowed	3	Alone	3	Nursing home	4
Children	10	Nursing home	1	Long-stay hospital	1

Table 6: Family structure and living arrangements of stroke patients (n=12)

Since this study concerns chronic illness, it was important to be alert to previous experience of illness and disability. Tables 7 and 8 show the range and type of health needs prior to the stroke. Only one patient had no identified health needs prior to the stroke. Each participant had at least one pre-existing illness for which they received some form of formal intervention. 6 people had 3 separate illnesses requiring intervention prior to the incidence of stroke. Table 9 indicates the type and level of formal carer involvement prior to the stroke. This illustrates that although stroke can be regarded as a sudden, violent transition from health to serious illness (Burton,

2000), in this study all but one participant had prior experience of ill health and of formal health services.

Type of illness	Number
Brain tumour	1
Rheumatoid arthritis	1
Osteoarthritis	1
Hypertension	5
Asthma	3
Dementia	3
Parkinson's disease	2
Chronic Obstructive Airways Disease	1
Psoriasis	1
Epilepsy	1
Eczema	1
Type 1 diabetes	1
Type 2 diabetes	2
Manic depression	1
Ischaemic heart disease	1

Table 7: Type of pre-existing illness prior to stroke

Number of illnesses	Number of participants
0	1
1	0
2	4
3	6
4	1

Table 8: Range of multiple pathologies

Professional group	Involvement	Number of participants
Consultant Neurologist	Out patient appointments	1
Macmillan nurse	Weekly home visits	1
Social services home care	Daily	5
GP/practice nurse	Regular appointments	8
Community psychiatric nurse	Weekly home visits	1
District nurse	Daily visits	1

Table 9: Type and level of formal carer involvement prior to stroke

The bodily experience of stroke influenced the illness trajectory at every stage in terms of management of unpredictable needs. Patients wished for full recovery and rehabilitation aims were often discussed in terms of cure and recovery. However, Table 10 shows both the immediate and long-term physical and emotional consequences of stroke and indicates that the majority of patients were left with considerable physical disabilities one year after stroke. Only 3 people made a full recovery and 1 female participant died just under a year following stroke.

Health needs	Number at 4 days post stroke	Number at 1 year post stroke
Aphasia (loss of speech)	3	1
Dysphasia (difficulty speaking)	5	3
Urinary incontinence	5	4
Faecal incontinence	2	4
Arm weakness	13	5
Leg weakness	8	6
Confusion	5	1
Depression	3	1
Loss of sight	1	0
Anxiety	1	1
Emotional lability	2	0
Difficulty swallowing	1	0
Full recovery	0	3
Death	0	1

Table 10: Immediate and long-term health consequences of stroke

Families in phase one

Table 11 shows the family characteristics and data collection methods used with each participant in phase one. The majority of participants held working class occupations and female participants predominantly adopted the caring role within the household. This creates the background for tensions at the interface in which formal carers and families sometimes made gendered assumptions concerning willingness or ability of female family members to take on an informal care-giving role. The carers in this study (n=10) were aged between 34 and 89 years of age and 2 were male, 8 female. Prior experience of caring appeared to influence the sense making process in this study. 1 carer came from a formal care background, and 5 people were able to recall previous care-giving experiences within the home. One of these care-giving

responsibilities ran concurrently with the experience of caring for the stroke survivor. 4 carers stated that the role was entirely new to them. Four of the carers were daughters of the patients, 2 were husbands and 4 were wives.

Table 11: Family characteristics in phase one

Patient name	Age	Sex	Occupation	Observation (hours)	No. of interviews	Carer (No. interviews)	Carer occupation
Catherine	42	F	Legal secretary	23.5	4	Husband (1)	Business entrepreneur
Susan	68	F	Housewife	12	2	Daughter (1)	Teacher
Margaret	83	F	Housewife	0	1	Declined access to carer	
Jim	84	M	Retired miner	14	Nil	Wife (2)	Housewife
Joseph	59	M	Ship joiner	40	1	Wife (3), daughter (1)	Housewife (both)
Anne	77	F	Retired cleaner	60	Nil	Daughter (3)	Housewife
Andrew	85	M	Retired builder	0	2	Declined access to carer	
Matthew	67	M	Retired mechanic	35.75	1	Wife (2)	Social services home carer
Ina	74	F	Retired teacher	60	2	Husband (2)	Retired shipbuilder
Adam	74	M	Retired tug worker	12.75	Nil	Daughter (3)	Shop assistant
Sally	71	F	Housewife	0	2	Informal carer declined to participate	
Simon	85	M	Retired solicitor	6	3	Wife (2)	Housewife

Formal carers

The questionnaire was designed to gain access to contextual data about the age, gender, professional group and experience of respondents. Of 31 respondents, 6 were male and 25 were female, with the majority (26) between 36 –55 years of age. Only 4 were between 25-35 and 1 was over 55. Table 12 indicates the range of professional experience among respondents. This shows that the majority of people were very experienced and had been in their current role for more than 6 years.

Number of years in current role	Number	Number of years since qualifying	Number
Less than 1 year	1	1-10	3
1-5	9	11-20	13
6-15	18	21-30	14
16-25	4		
More than 25	0		

Table 12: Range of professional experience among formal carers

Respondents worked in a variety of settings as shown in Table 13.

Work base	Number
General wards	17
Specialist rehabilitation wards	13
Day unit	2
Specialist stroke unit	6
Care of the elderly wards	4

Table 13: Work base for questionnaire respondents in phase one

Phase two

The children

There were 17 children in the phase two sample group, 8 of whom were female and 9 boys. At the time of interviewing, 7 children were between 3 and 10 years of age, ten were between 11 and 17 years. 2 children were in the school nursery, the remainder being in the main part of the special school. The incidence of chronic illness and its

effects on the whole family also influenced a decision not to have further children by a number of parents within the study. As shown in table 14, the majority or participants were the youngest child within their families. Similarly, parents sometimes alluded to the fact that the pressures of the illness led to marital breakdown. Table 14 indicates that 11 children lived with lone parents or with step-parents.

Place in family	Number	Living arrangements	Number
No siblings	2	With mother only	2
Older siblings only	7	With mother and siblings	5
Older and younger siblings	3	With father and siblings	1
Younger siblings	5	With mother, father & siblings	6
		With mother, step-father & siblings	3

Table 14: Family structure and living arrangements of children (n=17)

The children in the study had a range of health needs and illnesses requiring intervention by formal carers as shown in tables 15 and 16. Five children had an unplanned hospital stay during the course of data collection as a result of their chronic illnesses. Seven children used an electric wheelchair at all times as their mobility was so poor. Three children used self-propelled wheelchairs and one girl used a wheeled frame.

Health needs	Number
Spina bifida	3
Asthma	3
Polio	1
Eczema	4
Anaemia	2
Duschenne Muscular Dystrophy	3
Glutaric Acid Type One	1
Moderate learning difficulty	1
Chromosomal disorder	1
Leukemia	1
Cerebral Palsy	4
Brittle Bone Disease	1
Rheumatoid arthritis	1
Profound deafness	1
Glue ear	1
Registered blind	1
Cystic fibrosis	1
Type 1 diabetes	1

Table 15: Types of health needs experienced by the children

Number of health needs	Number of children
One	7
Two	7
Three	2
Four	1

Table 16: Range of combined health needs

In addition, 6 of the children were dependent on technology or mechanical aids to deal with their health needs as shown in table 17. Their parent(s) required training to become competent to deal with these technologies in the home environment.

Technological dependence	Number
Gastrostomy	2
Parenteral nutrition	1
Urethral catheter	2
Tracheostomy	1

Table 17: Technological dependencies of the children

Families in phase two

The family characteristics are shown in table 18. These show the chronic illnesses experienced by individual children in the study and the duration of these illnesses. Nine children were diagnosed at birth or soon after, with the remainder being diagnosed from the ages of 4 onwards. Ten mothers were included in the study, and 5 fathers. The children in the study were asked to identify their informal carers and only one sibling was identified as being a carer at the start of the study.

Table 18: Family characteristics in phase two

Name	Age	Sex	Ethnic origin	Health Needs	Duration of chronic illness	Observation (hours)	No. of interviews	Carers (no. interviews)
Lucy	12	F	White	Spina bifida, asthma	Since birth	40	3 *	Mother (2)
Hanif	16	M	Bangladeshi	Polio	For 12 years	30	2 *	Father (2)
Liam	15	M	White	Duschenne muscular dystrophy	For 7 years	30	2 *	Father (2)
Billy	10	M	White	Glutaric acid type one	Since birth	6	1	Mother (1)
Toby	7	M	White	Chromosome abnormality, leukaemia	For 4 years	12.5	0	Mother (2)
Rebecca	15	F	White	Cerebral palsy	Since birth	35	2 *	Mother (2)
Simon	15	M	White	Spina bifida	Since birth	30	2	Mother (1)
Kate	8	F	White	Brittle bones, asthma, eczema	Since birth	28.5	1 *	Mother declined to participate

Table 18: Family characteristics in phase two(continued)

Name	Age	Sex	Ethnic origin	Health Needs	Duration of chronic illness	Observation (hours)	No. of interviews	Carers (no. interviews)
Jake	11	M	White	Duschenne muscular disease	For 3 years	40	2 *	Mother and Father (1)
Monica	11	F	White	Cystic fibrosis, diabetes, asthma	For 6 years	40	2	Mother (2)
Andrew	4	M	White	Cerebral palsy	Since birth	22.5	0	0
Mary	12	F	White	Head injury	For 3 years	26.5	0	0
Carrie	3	F	White	Profoundly deaf	Since birth	24.5	0	0
Debbie	10	F	White	Juvenile arthritis	For 6 years	17.5	1	0
Peter	14	M	White	Duschenne muscular dystrophy	For 6 years	30	2 *	Mother, father and sister (1)
Sam	17	M	White	Cerebral palsy	Since birth	6	1 *	Mother and father (1)
Isabel	6	F	Pakistani	Spina Bifida	Since birth	12	0	Mother (1)

*** Indicates children who took photographs**

Formal carers

The questionnaire in phase two was again designed to gain access to contextual data about the age, gender, professional group and experience of respondents. Of 42 respondents, 7 were male and 35 were female, with the majority (31) between 36 – 55 years of age. Only 7 were between 25-35 and 3 were over 55. Table 19 indicates the range of professional experience among respondents. This shows that the majority of people were very experienced and had been in their current role for more than 6 years.

Number of years in current role	Number	Number of years since qualifying	Number
Less than 1 year	5	1-10	8
1-5	12	11-20	18
6-15	18	21-30	16
16-25	7		
More than 25	0		

Table 19: Range of professional experience among formal carers in phase two

Respondents worked in a variety of settings as indicated in Table 20. The majority of respondents working in mainstream units chose to complete questions about case-study A (n=27), while those working in special schools chose case study B (n=4) and C (n=10).

Mainstream school with unit for:	Number	Special school for:	Number
Physically disabled children	5	Physically disabled children	12
Hearing impaired children	3	Hearing impaired children	7
Children with visual impairment	4	Children with visual impairment	1
Children with learning difficulties	7	Children with learning difficulties	2
		Hospital paediatric unit	1

Table 20: Work base of questionnaire respondents in phase two

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Coping strategies used by hospitalized stroke patients: implications for continuity and management of care

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This paper describes findings from an English study into the perceptions of multi-professional practice given by stroke patients, their informal carers and hospital staff. Unstructured interviews were conducted with nine stroke patients and eight informal carers. Case studies were developed from the interview data which formed the basis of a questionnaire designed to ascertain the aims of care for the case studies and the location of professional responsibility for meeting these aims. This was returned by 31 respondents from a range of professional backgrounds. The findings indicate that patients and carers sought out relationships with staff and other patients in order to gain information to help them understand their uncertain futures. Professional staff were reluctant to pass specific information on to patients as it might be misleading in each individual case. The uncertainty surrounding individual recovery means that supportive relationships initiated by patients and carers may need to be recognized and nurtured.

Keywords: stroke rehabilitation, multi-professional teamwork, coping, uncertainty

INTRODUCTION

A large body of literature exists on the impact of multi-professional developments on agendas and resource management strategies of professionals (Department of Health 1993, Chapman 1994). Analysis of recent policies produced in the United Kingdom reveals a concern not only for these issues but also for issues of patient agendas such as consumer choice and the rights of patients to be part of the multi-professional collaboration and decision making process (Department of Health & Social Security 1989, Department of Health 1996). For instance, the recent policy document *NHS: A Service with Ambitions* has added a fourth principle to the founding principles of the National Health Service (NHS) and that is that the NHS should be 'responsive' to users as consumers of health care (Department of Health 1996). This study explores the assumption that the issue of multi-professional collaboration is 'inextricably linked' to the issue of consumer

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participation (Greenwell 1995) and that in order to gain understanding of each of these, they should be looked at as interrelated concepts, rather than as discrete issues.

For the purpose of this paper, the parallel concepts of user perspectives and multi-professional teamwork, analysed in the context of the care needs of stroke patients, are used as a tracer condition to explore these issues. There is considerable debate in health care concerning the nature of therapeutic interventions by professional groups working with stroke patients. Authors disagree over the appropriate roles of particular groups of staff working with stroke patients (Myco 1984, O'Connor 1993), and more specifically about the role of the patient in multi-professional decision making (Waterworth & Luker 1990). In order to explore some of these issues a district general hospital that admits stroke patients was chosen as the focal point of this study.

The objectives of the study reported in this paper were to explore:

- stroke patients' perceptions of their needs and interpretations of progress;
- carers' perceptions of their own needs and those of the patient, and carers' interpretation of the progress made by the patient; and
- ways in which different professional groups define their own contributions and the contributions made by other professional groups in identifying and meeting the needs of stroke patients.

METHODS

Following approval from the NHS District Ethics Committee, four general medical wards in a general hospital were chosen for this study and convenience sampling was used (Robson 1993) in the sense that every stroke patient admitted to the wards became a potential participant. Ethnographic observation was carried out with four stroke patients using a schedule developed during the pilot phase of this research. The schedule was designed to elicit the type and number of staff who came into contact with patients and the nature of each interaction between patients and staff. In the tradition of grounded theory (Strauss & Corbin 1990) a number of themes emerged from the observation which guided the direction of further enquiry.

These directions were followed in interviews with stroke patients and their informal carers. A series of unstructured, qualitative interviews were carried out with nine stroke patients and eight informal carers. Up to four interviews with both patients and carers (either separately or together) were conducted throughout the stay of each patient in hospital. When appropriate, follow-up interviews were conducted with patients and carers, again either separately or together, following discharge from hospital. Table 1 describes the age and gender of the patients who agreed to participate in this research. It also gives the length of hospital stay for each participating patient, the number of interviews conducted with each patient and each carer and identifies those patients who, additionally, were observed as well as interviewed. Constant comparative analysis was used throughout the process of data collection to develop themes and refine future interviews. Transcripts were coded using techniques advocated by Strauss & Corbin (1990).

Following the analysis of the interview data two theoretical case studies, which reflected the main issues to arise for patients and their carers, were developed and used as the basis for a questionnaire. The questionnaire consisted of open ended questions relating to the aims of care for the theoretical case studies and the location of professional responsibility for meeting these aims. Table 2 describes the respondents to the questionnaire by professional group. All respondents were currently working with hospitalized stroke patients across a total of 10 NHS Trusts. Again, analysis used the constant comparative method and involved the use of coding techniques.

FINDINGS

Analysis of the interview data revealed that patients and their carers expressed considerable uncertainty about the patient's prognosis and rehabilitation. The early interviews were dominated by a search for more definite information and a feeling that professional staff were not passing information on to them.

Expressing uncertainty about stroke rehabilitation

Patients and carers alike expressed uncertainty about how long the patient would be in hospital, the patient's prognosis and the possible trajectory of the illness. One patient said:

> .... there's always the fear of it happening again. That's sort of there. You know, I'm trying not to think about it and people have told me it's a one-off thing. You know there's no reason why it should happen again, but if you knew why it happened in the first place, it might help.

Carers also expressed uncertainty about the impact the stroke was going to have on their lives following the discharge of the patients from hospital. They were unsure about what additional support they would need to help look after the patients following discharge. They were also uncertain as to what support would be offered or could be expected. Concern was also expressed by carers about how they would adjust emotionally to the changes in their relationship with the patient engendered by the stroke. One carer said:

Table 1 Interviews and observation periods

Code	Age	Gender	Hospital stay	No. of interviews	Observation period
Patient A	42	F	22 days	4	–
Carer A	50	M	–	1	–
Patient B	68	F	22 days	2	–
Patient C	83	F	21 days	1	–
Patient D	84	M	43 days	0	–
Carer D	82	F	–	2	–
Patient E	59	M	94 days	1	–
Carer E	57	F	–	4	–
Patient F	77	F	116 days	0	15 hours
Carer F	51	F	–	3	–
Patient G	85	M	21 days	2	6 hours
Patient H	67	M	123 days	1	8 hours
Carer H	63	F	–	3	–
Patient I	85	M	42 days	2	–
Carer I	63	F	–	2	–
Patient J	74	F	63 days	0	12 hours
Carer J	78	M	–	3	–
Patient K	74	M	21 days	1	–
Patient L	71	F	47 days	3	–

I'm not sure how things are going to affect my future. You look on the black side, you know.

Another said:

He was my best friend. We discussed everything. Now he can't even tell me when he needs to go to the toilet. I miss him.

Another said:

I'm sick myself. I'm on permanent invalidity 'cos of my back. I just don't know how they think I'm going to manage her on my own, in that house. I'm having sleepless nights just thinking about it. What am I going to do?

Seeking information about stroke rehabilitation

Patients and carers alike wanted detailed information about the possible pattern of rehabilitation. In other words, they wanted detailed and immediate assurances about the extent to which the patient would recover and a prediction of how long this recovery might take. Patients asked members of staff direct questions about their prognosis and although these were never answered with specific assurances, patients and carers alike felt that members of staff, in particular nurses and doctors, were party to information, knowledge and opinions about their prognosis. One patient said:

I know there's no time limit on it, but I think staff must sort of know up to a certain extent about how things are going to go.

A carer said:

... you can't really find out much about when he'll get better, you know. They just say, oh, well, time you know. So you don't really know.

Interestingly, it was felt by interviewees that information was either directly withheld or was presented in a general, indirect way which did not tell them what they wanted to know. One carer said:

You think, well, do they [staff] know, because when it first happened and I asked one of the nurses, they said, oh, you have an idea between 6 and 7 weeks how things are going to go, you know.

From the patient's and carer's perspective there was an expectation, in the early stages of the illness, that professional staff must be in a position to provide more concrete and definite information about the expected length of hospital stay and the condition of the patient on

Table 2 Questionnaire respondents

Professional group	No. of respondents
Doctors	5
Staff nurses	5
Social workers	2
Physiotherapists	6
Speech therapists	10
Occupational therapists	3
Total	31 (50% response rate)

discharge. In order to counteract the perceived lack of information provided by professional staff, many patients and carers developed a range of tactics to obtain information. These tactics involved seeking out other stroke patients, carers, other friends, family and staff who were thought to have knowledge about rehabilitative processes associated with having a stroke, and seemed willing to pass this information on.

I know I talk to different people at home and they say 'Oh, we've been through it all and we've come through remarkably well'.

A patient said:

My brother-in-law, he had two strokes and he died... so I've been very fortunate, very, very fortunate.

As far as the stroke's concerned, I know nothing about them apart from what you hear from other people in the ward who's had them.

Both patients and carers were proactive in initiating these contacts in order to seek out further information on other people's experiences of stroke and stroke rehabilitation. Through these informal information networks, patients and carers began to realize that concrete facts about stroke rehabilitation were limited and that most of the information they received about other people's experiences of stroke and stroke rehabilitation was conjectural and was based on feelings and opinions. Over time, patients and their carers came to understand the uncertainty surrounding the patient's prognosis and rehabilitation and the difficulties associated with providing definite information about outcomes for a given individual. As acceptance of this uncertainty developed, patients and their carers began to realize that the emotional support given by people was more important in helping them deal with the reality of their situation, than the search for elusive information about prognosis and outcomes. However, it was through the search for elusive information about prognosis and outcomes that patients and their carers came to realize the reality of uncertainty and the importance of emotional support in helping them to live with uncertainty. Later interviews indicated an acceptance of uncertainty as an essential attribute of living with a stroke.

But the staff haven't really got time to talk to you because of the pressure... well, it's hard for them when they don't know the answers to your questions. I catch their eye... they just say I've got to be patient and wait for him [husband] to recover in his own time.

I know it's just a matter of time but it's so hard, really frustrating, so when the nurses have got time, I sit and cry and cry... to me that's what counts. I can't have answers... but at least they sit and hold my hand.

Within this situation, patients were able to identify key members of staff who they regarded as being trustworthy and supportive. One elderly patient said:

I mean all you need is somebody on your side and the female doctor came and sat and talked and she was wonderful.

Patients described how they attempted to develop relationships with staff members and there was some qualitative evidence that the staff members identified by the patient were of a similar age, class and/or gender to the patient who had identified them.

Professionals' perceptions of stroke rehabilitation

The questionnaire was developed in order to explore some of these issues in relation to staff perceptions of multiprofessional practice. Questionnaire data revealed a general consensus among professional staff as to the expected length of hospital stay, prognosis and rehabilitative trajectory for the case studies outlined. Most of the aims identified by professional staff focused on physical needs and some on improving the mental health of the patient. Interestingly, only the speech therapists identified the long-term aim of educating and emotionally supporting the patient and family through the transition period and following discharge. It is notable that speech therapists were the only professional group where the same practitioner provided treatment to the patient while in hospital and then following discharge into the community. It is possible that their recognition of the educational and emotional needs of the patient and their families was reflective of this difference rather than anything arising from their professional role.

Responses to the patients' and carers' needs for information were general rather than specific. The therapists and social workers referred the patient to the consultant for information. Nurses and doctors tried to address these issues themselves, some suggesting the use of statistical information (for example some suggested a one in 10 risk of further stroke). Most respondents said they would tell the patient that most stroke victims do make some improvement. For example, a speech and language therapist stated that:

I would tell the patient that she might have another stroke, also encourage her to be positive about her strengths.

In contrast, some respondents felt that it would be better to protect patients from information about their prognosis. One staff nurse stated:

If her family don't want her to know, we should not tell her even if we don't agree with their policy.

DISCUSSION

The findings from this study present a view of the patient as being someone who proactively, without explicit guidance, builds supportive relationships and gains knowledge and information from those around him/her in order

to counteract the experience of uncertainty associated with having a stroke. This proactive behaviour can be linked with literature on coping with illness events such as a stroke. This literature points to the fact that these patients were actively using problem focused strategies. Problem-focused strategies are described by Billings & Moos (1981) as situations in which a person attempts to modify or eliminate the sources of stress through their own behaviour.

While rehabilitation therapists have tried consciously to move away from viewing the role of the patient as passive recipient to that of active collaborator in their care, it is still possible to view traditional rehabilitation in terms of the stress-mitigation model (Glass & Maddox 1992). Within this model, illness events such as a stroke are seen as inherently stressful, negative and damaging. This reinforces the picture of the passive patient who needs therapy to overcome these stresses. While not denying that therapy is needed following a stroke, patients' accounts of their experiences add a new dimension to this picture, highlighting the type of collaborative engagement that would be valued by these patients and indicating how the energies of the patient and their carers could be harnessed to promote a greater mutual understanding of the situation.

Looking at the implications of the findings for the management of nursing care, there is qualitative evidence to suggest that, whether the ward used primary nursing or team nursing, the patient would proactively identify and cultivate a relationship with a nurse (either trained or auxiliary) or another member of the hospital staff and would value that relationship very highly in terms of coping with the effects of the stroke. Unfortunately, organizational constraints existed which made it difficult for staff to work through issues of uncertainty with patients and their families. Bennett (1996) has identified similar constraints on a specialized stroke unit that included lack of time and the precedence given to physical care. In addition, in this study, lack of continuity of care was an issue, either because of staff shortages or because the patient was transferred to another ward early on in treatment. It is probable that each of these constraints prevented staff from assisting the stroke patients and their families through the grieving and coping processes.

This study is particularly illuminating in the context of the current debate in nursing about patient participation and collaboration in the process of care. Waterworth & Luker (1990) conducted a qualitative study of this issue and concluded that 'obeying the rules' or 'toeing the line' was the course of action adopted by the patients in their study. Patients accepted the authority vested in the expertise of the professional staff and consequently felt that their lay knowledge did not provide them with an appropriate basis for challenging this expertise. Waterworth and Luker concluded by suggesting that, given the propensity to conform displayed by patients in their study, patients would also conform with collaboration whether they wished to or not. As Waterworth and Luker fully acknowledge, the expertise that the patients sought from professional staff was vested in the medical model of care and was based on technical knowledge.

It is interesting to contrast the findings of Waterworth & Luker (1990) with the findings of this study. Both studies used a similar methodology and sample size, although this study undertook a series of interviews over time with the same patient and carer. Moreover our study concentrated on a single diagnostic category. In both studies, patients and their carers respected medical expertise and in fact wanted it to be shared more fully with them. This expertise was required in order for the patients and carers to gain insights into the patients' potential for recovery and to make decisions about the future. Professional staff on the other hand felt reluctant to share their expertise with patients because of the large element of uncertainty surrounding the extent to which a given individual will recover. The longitudinal data collected in our study indicated that patients and their carers gradually became aware of and learnt to live with the uncertainty surrounding outcomes, through discussion with other patients, neighbours, family, friends and some staff.

These findings suggest that in seeking participation, patients do not necessarily want to be involved in technical decisions about their care, rather they are seeking expertise from professionals to help them understand their own futures. When professionals are unable to give them certainty in relation to outcomes, patients and carers are able to accept this. Under these circumstances participation can be re-defined as a mutual exchange of knowledge with professionals imparting their expertise with all its limitations, and the patient or carer providing information on the impact of the stroke on their lives and on how they are going to cope in the future. This often spills over into considerations of the social role and family relationships.

Developing relationships within multi-professional collaboration

The issue of continuity of care and continuity of carer becomes even more complex when viewed in a multi-professional context. Observation data from this study indicated that patients often had more contact, and therefore more time for discussion, with physiotherapists and occupational therapists than with their primary nurse. Tensions and conflict between professional groups are well documented in terms of negotiation of roles in rehabilitation (Iles & Auluck 1990, Dingwall & Lewis 1992, Reed 1993). As nurses providing 24-hour care to

patients, we often assume that we are best placed to provide psychological and emotional support for patients. It can be a bitter pill to swallow if a patient rejects this provision and instead chooses a physiotherapy aide or a porter to befriend. Yet, if we accept that this happens, we might go some way to developing organizational structures and mechanisms to support this for the benefit of the patient.

Similar issues have been identified by research into the uncertain world of cancer care. In the past 30 years, research by Bond & Bond (1986) and others, on diagnostic and prognostic information given to patients with cancer, has led to an understanding of staff–patient relationships in situations where, like stroke rehabilitation, uncertainty is a day-to-day reality for staff and patients alike. Research has shown that nursing and medical staff are often reluctant to communicate with terminally ill patients and to deal with uncertain issues for many reasons concerning resources, the ward environment and work organization (Payne & Firth-Cozens 1987). An awareness of these issues has led to changes in services for terminally ill people. For example, in many areas of the UK, the hospice movement is seen as an umbrella of care encompassing community, hospital and hospice care. In those directorates where this ideal is a reality, the use of flexible staffing arrangements means that patients can often be cared for by the same nurse, or group of nurses, at home and in the hospice (Field & James 1994). In addition, day care facilities, where available, give patients an opportunity to meet with one another and discuss problems and feelings with each other. It has to be said that at present this system is often *ad hoc* and difficult to implement but it does go some way to addressing the issue of continuity of carers (Procter 1995), and of providing contact with other patients in a way that builds on the coping strategies used by patients and their carers.

Today, in the UK we are seeing a national trend towards the creation of specialized stroke units designed to improve rehabilitative outcomes (Strand *et al.* 1985). It seems clear that even in these units, the medical model takes precedence in the sense that priority is given to physical therapies and outcomes (Starkstein & Robinson 1989). A plethora of research shows that if stroke patients' psychological needs are not addressed, this will adversely affect their physical rehabilitative outcome (Schubert *et al.* 1992, Glass & Maddox 1992, Bennett 1996). The proactive coping strategies demonstrated by patients in this study, alongside the example of the hospice movement, provides a strong foundation for practitioners to build on. The development of specialized stroke units offers us the opportunity and the resources to address the psychological and emotional needs of patients. This opportunity must not be missed if we are really to operationalize the concept of individualized patient care.

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